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Pepperdine University  
Graduate School of Education and Psychology

SOCIAL MEDIA AND SOCIAL SUPPORT:  
A USES AND GRATIFICATIONS EXAMINATION OF HEALTH 2.0

A dissertation submitted in partial satisfaction  
of the requirements for the degree of  
Doctor of Education in Learning Technologies

by

Lydia Sunnie Kim

January, 2016

Linda Polin, Ph.D. - Dissertation Chairperson

This dissertation, written by

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under the guidance of a Faculty Committee and approved by its members, has been submitted to and accepted by the Graduate Faculty in partial fulfillment of the requirements for the degree of

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## ABSTRACT

An increasing number of people are using the Internet for health purposes. Online social media makes it possible to find and share health-related information and to find social support by connecting with others who have the same issue or condition. This is true not only of patients or people experiencing health issues, but also of their caregivers. So far, little is known about caregivers' use of social media for social support purposes. This study focused on caregivers of children of Down syndrome and implemented a uses and gratifications framework to examine their social media use, motivation, and perceived support outcomes. An online survey was followed by a content analysis of two popular social media sites utilized by the sample. Findings suggest that caregivers are indeed heavy social media users with the majority accessing their preferred sites on a daily basis to view content and at least once a week to post their own content or reply to content posted by others. The strongest motivation for using social media was to connect with people who understood what they were experiencing. Having access to other parents with children the same age and/or with the same medical conditions was a significant motivation for using social media over face-to-face support groups. Belonging support (the sense of belonging to a group similar to oneself) was also the highest perceived outcome of social media use. Caregivers felt that there were people who shared their same concerns and interests on their preferred social media site. Finding emotional support was another strong motivation for using social media and informational support was the second highest perceived outcome from social media use. This study sheds light on how caregivers use social media for support purposes and provides practical suggestions for improving the capacity of other health or care-related online communities focused on providing social support to better serve the needs of their users.

## **Chapter 1. The Problem**

For parents of children with genetic conditions, receiving the initial diagnosis is often shocking and can be described as a crisis situation (Selikowitz, 2008; Skotko, 2005). For those who receive the diagnosis shortly after giving birth, the experience is even more difficult since they are already in an emotional and vulnerable state from the labor and delivery process and have not had a chance to get to know their child as an individual before he or she is labeled with a syndrome or condition (Selikowitz, 2008; Skotko, 2005). After the diagnosis, parents are often overwhelmed by the unknown and feel helpless as they mourn the loss of the healthy child they expected or desired and now need to manage their child's complex medical needs (Abery, 2006; Choi, Lee, & Yoo, 2011; Skotko, 2005). Feelings of fear and anxiety are oftentimes exacerbated when healthcare professionals provide parents with a bleak outlook and point out only the negative aspects of the condition (Choi et al., 2011; Skotko, 2005; Skotko, Capone, & Kishnani, 2009). Parents of children with genetic conditions also experience unique feelings of guilt for passing on the condition to their child (McAllister et al., 2007).

### **Background**

Every year, one in every 691 babies in the United States is born with Down syndrome, a genetic condition that occurs when an individual has a full or partial extra copy of chromosome 21, making their total chromosomal count 47 instead of the typical 46 (National Down Syndrome Society [NDSS], n.d.). Down syndrome, also known as Trisomy 21, is the most commonly occurring genetic disorder and it is estimated that there are more than 400,000 people living in the United States with the condition (NDSS, n.d.). Although the range varies, people with Down syndrome experience physical and cognitive developmental delays and have an increased risk for certain medical conditions such as congenital heart defects, respiratory and hearing problems,

Alzheimer's disease, childhood leukemia, gastrointestinal issues, and thyroid conditions (Centers for Disease Control and Prevention [CDC], 2013; GeneFacts, n.d.; Sherman, Allen, Bean, & Freeman, 2007.).

Parents of children diagnosed with Down syndrome and other genetic conditions experience high levels of emotional stress as well as high levels of caretaking demands (Gunderson, 2011; Mullins, 1987; Singer & Irvin, 1989). They need to continually monitor their child's health status as well as manage multiple medical, therapy, and educational appointments (Krahn, 1993; Mullins, 1987; Singer & Irvin, 1989). A significant stressor for parents is not knowing how the condition will impact their child's future prospects or what the probable medical, intellectual, or social consequences of the condition may be (Gunderson, 2011; McCallister et al., 2007).

One strategy for coping with the stress of caring for a child with special needs is seeking and receiving social support. Weiss (1974) classifies the functions of social support into the following categories: guidance, reliable alliance, reassurance of worth, opportunity for nurturance, attachment, and social integration. *Guidance* can come in the form of advice or information and is also described as instrumental or informational support. *Reliable alliance* is the assurance that others can be counted upon for tangible assistance or material support. *Reassurance of worth*, also known as esteem support, is the recognition of one's competence, skills, and value by others. *Opportunity for nurturance* deals with feelings of responsibility for the well-being of another. *Attachment*, or emotional support, describes emotional closeness that produces a sense of security. *Social integration* is a sense of belonging to a group that shares similar interests, concerns, or recreational activities. This is also known as network or belonging support (Weiss, 1974; Cutrona & Russell, 1987).

While some of these social support functions can be fulfilled by family members and close friends, some support functions are better fulfilled by those who have gone through similar experiences and can understand what the situation and all its implications entail (Preece, 1999). Although local face-to-face support groups are a source of social support for some, for many who are working around a child's schedule and needs, going to a physical location at pre-designated times can be difficult, if not impossible (Coulson & Knibb, 2007; Sharf, 1997; Weinberg, Schmale, Uken, & Wessel, 1995; Wright 2000). Online support communities have become a popular way to find support for people dealing with all kinds of medical issues. The asynchronous nature of most online support applications allow users to participate when they want and also catch up if they were not able to participate for a period of time (Weinberg et al., 1995). The time and location independence of Internet communications, as well as the ease and speed of accessing online support from home, especially in light of work and family commitments, makes online support services a popular option over face-to-face support groups (Coulson & Knibb, 2007; J. Leimeister, Schweizer, S. Leimeister, & Krcmar, 2008).

A study by the Pew Research Center on peer-to-peer healthcare found that one in five Internet users have gone online to find others who might have health concerns similar to their own (Fox, 2011). Numerous studies on online social support for health-related issues have shown that Internet communications with people experiencing similar diseases or conditions can have positive impacts on emotional health and well-being (Attard & Coulson, 2012; Chung & Kim, 2008; Coulson, 2005; Coulson & Knibb, 2007; Høybye, Johansen, & Tjørnhøj-Thomsen 2005). Key avenues of support involved in this type of peer-to-peer online communication include informational support, emotional support, belonging support, and active support (Ancker et al., 2009; van Uden-Kraan et al., 2008). The type of information exchanged in online social

support groups or communities can include guidance or advice, personal experience, perspectives on treatments, and ratings and reviews on health services. The types of emotional support experienced by participants in online support groups and communities can include feelings of empowerment and self-efficacy, improved acceptance or ‘normalizing’ of the condition, increased hope and optimism, and enhanced self-esteem (Stellefson et al., 2013; van Uden-Kraan et al., 2008; Ziebland & Wyke, 2012). Belonging support often comes in the form of a sense of belonging to a group and the reduction of feelings of isolation (Coulson & Knibb, 2007; Høybye et al., 2005). And finally, active support describes the opportunities to help others, which can result in raised self-esteem and finding meaning in one’s own experience (Høybye et al., 2005).

### **Researcher Background**

When my son was three weeks old, we learned that he had a genetic condition called an unbalanced translocation, which occurs when affected chromosomes have extra or missing genetic material. The diagnosis explained the many health issues he had been experiencing since birth. I remember sitting in the doctor’s office trying to hold back my tears as I learned that he would most likely have developmental delays and cognitive deficits. A few weeks later I learned that I was the one who had passed on the condition to my son. Unlike him, however, I had a balanced translocation, which means that the genetic material in the affected chromosomes merely switched places resulting in neither extra nor missing material.

The first year of my child’s life was filled with appointments to see doctors, specialists, and therapists. I was exhausted and functioning in survival mode as I solely focused on getting him the best care. But in the moments where I had time to sit and think, I would be overwhelmed with feelings of grief, anger, and guilt. I grieved for the “normal” future I had always envisioned

for my child; I was angry that he had to go through so much at such a young age; and I felt guilty because I was the one who had given him this condition. None of my friends or family could really understand what I was experiencing and I felt isolated and alone. One way I coped with my emotional stress was by going online and reading the personal narratives of other parents of children with genetic conditions or special needs. During feedings and nap times, I would read blog after blog written by people who were going through or had gone through similar experiences and emotions as my own. The online community of parents of children with special needs became the rope that pulled me out of my despair by showing me that it gets better and that my child could still thrive and be happy. My experience with the online support community was the motivation behind this study.

## **Problem**

Although there is extensive research on health-related online social support, most studies are of patients with chronic diseases such as cancer or diabetes or other common health conditions. Studies on online social support for people with rare or genetic conditions and for caregivers of individuals with those conditions are relatively sparse. In addition, most research to date on online social support is focused on earlier online communication mediums such as discussion boards and email mailing lists. Although social media applications are now ubiquitous with how people connect online, research on social media in relation to online social support for health purposes is in its infancy. Resources found through online social support mediums can provide important information and emotional support for people dealing with health-related issues. This study provides research into the use of social media in the context of online social support by caregivers of children with special needs related to a genetic condition.



## **Purpose**

The purpose of this mixed methods explanatory sequential study was to utilize a uses and gratifications framework to examine how caregivers of children with Down syndrome use social media to access social support. In the first phase, quantitative data was collected on respondents' choice of social media applications, motivations, perceived social support outcomes, and background information. The second phase used responses from the first phase to select specific social media sites to examine using a qualitative content analysis.

### **Research questions.**

RQ1. How do caregivers use social media for social support purposes?

RQ2. What are caregivers' primary motivations for using social media for social support purposes?

RQ3. How does the use of social media mediate caregivers' perception of social support outcomes?

## **Significance of the Study**

This research adds to the body of knowledge on social media and online social support, which is currently in its infancy. Findings from this study can provide insight into the motivations and perceived outcomes of social media use for support purposes. This information can be used to provide guidelines that can help online communities provide richer supportive environments.

## **Chapter 2. Literature Review**

The Internet has profoundly changed the way people communicate and engage with each other. The ever-growing list of online tools and services allow people to connect, interact, contribute, and collaborate in ways never imagined before. These tools, known as social media applications, democratize the Internet by blurring the traditional boundaries that once were barriers to access such as location, status, profession, and time. This phenomena is especially visible in the field of health care and management as people use the Internet to empower themselves with information and find support from others like them. In order to examine and understand how health-related social support needs of caregivers are met through online engagement in social media activity, the following constructs will be discussed:

- Uses and gratifications theory
- Social media
- Health 2.0
- Social support
- Online social support
- Caregiver support needs

### **Uses and Gratifications Theory**

The uses and gratifications theory is a mass communication approach that asserts that media use can be explained by the user's motives and needs (Katz, Blumler, & Gurevitch, 1973). This theory assumes that people are goal-oriented and actively seek and use media that best gratify specific needs. Therefore, people are more likely to use and continue to use a medium if it effectively gratifies the need they are seeking to fulfill. Rayburn and Palmgreen (1984) refined the theory by differentiating between gratifications sought by the user and gratifications actually

obtained from the use of the media. This implies that the gratifications a person *expected* to receive from a media may be different than the gratifications the person *actually* receives.

Born out research on media effects, this approach countered earlier mass communication theories that portrayed the audience as passive, easily influenced, and uniformly affected by media messages (McQuail, 2010). This audience-centric approach focuses on what people do with media rather than the influence or impact media has on the individual. Katz et al. (1973) point out five basic assumptions that underlie this theory:

1. Audience members, or users, are active and their media-use is goal directed.
2. Users are the ones who take the initiative to link need gratifications with their media choice.
3. The media is just one way to satisfy needs and so it competes with other sources of need satisfaction.
4. In terms of methodology, people have enough self-awareness of their own media use, interests, and motives to provide researchers with an accurate picture of that use.
5. Only the user can assess value judgments regarding the content communicated by the media.

Earlier research on uses and gratifications focused on traditional forms of media such as television, radio, newspaper, and film. Rubin, Perse, and Barbato (1988) drew from that previous research along with research on interpersonal needs to identify six major motives for interpersonal communication: pleasure, affection, inclusion, escape, relaxation, and control. Recent studies have increasingly used the approach to examine new media and online technologies. With higher levels of interactivity, computer mediated communications and online technologies lend themselves well to the uses and gratifications approach (Ruggiero, 2000).

Papacharissi and Rubin (2000) identified five primary motives for using the Internet: interpersonal utility (socially-oriented behavior), to pass time, information seeking, convenience, and entertainment. Information seeking was found to be the most prominent use of the Internet.

Leung (2013) utilized the uses and gratifications approach to examine users of social media, specifically Facebook, blogs, and forums. The study found that content generation using social media gratified five socio-psychological needs: showing affection, venting negative feelings, gaining recognition, getting entertainment, and fulfilling cognitive needs. Studies using the approach to examine social media use for health-related activities found related gratifications such as emotion management and information sharing (Chung, 2013; Chung & Kim, 2008).

## **Social Media**

The term ‘social media’ is ubiquitous now with the way we interact and engage with the Internet. When thinking about the current landscape of social media, applications like Facebook, Twitter, or YouTube may immediately come to mind. But ten years ago, it could have been MySpace or Xanga. New social media platforms and applications are developed every day while old ones become obscure and die out. Therefore, in order to explore social media as a construct, it needs to be separated from the individual applications that are currently associated with it and be considered within the context of its functions and purpose. Kaplan and Haenlein (2010) define social media as “a group of internet-based applications that build on the ideological and technological foundations of Web 2.0, and that allow the creation and exchange of User Generated Content” (p. 61). To fully understand this definition, the following section will examine the concepts of Web 2.0 and user generated content.

**Web 2.0 and user-generated content.** In the computing world, the term “read-only” describes an access permission level for a file or application where the user can only read or

view the content *as-is*. A “read-write” permission level, on the other hand, allows users to not only view the content, but also to add-to and change it. These two levels of accessibility illustrate the difference between Web 1.0 and Web 2.0 (Wenger, White, & Smith, 2009). Whereas the first generation of web content was published by individuals in the form of static webpages and brochure sites, the second generation of web content is dynamic and “continually modified by all users in a participatory and collaborative fashion” (Kaplan & Haenlein, 2010, p. 61).

The shift to Web 2.0, or a *read-write* web, occurred as new online tools and platforms allowed all users to utilize the World Wide Web in an active, participatory, and collaborative way. Web 2.0 represents a paradigm shift in the role of the public; no longer relegated to being mere information consumers, the new generation of Internet users are identified as information *prosumers* – users who consume *and* produce content (Kamel Boulos & Wheeler, 2007). Empowered with tools and applications that promote social interactions through information sharing, content creation, online collaboration, and social networking (Kamel Boulos & Wheeler, 2007; Doherty, 2008; Sarasohn-Kahn, 2008), “the category of ‘consumer’ is now a temporary behavior rather than a permanent identity” (Shirky, 2008, p. 108). Built on the ideological and technological foundations of Web 2.0, these tools are now widely known as ‘social media’ (Kaplan & Haenlein, 2010).

When people use social media, user-generated content is the product or result (Kaplan & Haenlein, 2010). Content created by Internet end-users comes in a variety of forms and mediums including (but not limited to) blog posts, videos, photos, audio podcasts, and ratings and reviews. According to the Organization for Economic Cooperation and Development (Vickery & Wunsch-Vincent, 2007), user-generated content is defined using the following criteria:

1. It is published on a publically accessible website or on a social networking site only accessible to a select group of people (excludes email and instant messaging communications).
2. A certain amount of creative effort was put into creating or adapting existing work to construct a new one (excludes posting a copy of something without any modifications or commenting).
3. It is created outside of professional routines and practices (excludes content created for an institutional or commercial market context).

To reiterate Kaplan and Haenlein's (2010) definition, social media, then, are the tools that support the ideals of Web 2.0 and enable Internet end-users to create and share content. In the next section, these tools will be identified and classified into categories based on existing psychosocial and media theories.

**Social media classification.** Wikipedia, Facebook, and YouTube are globally known social media behemoths that have become game changers in the way people interact with the Internet and with each other. However, thousands of social media applications have been developed that provide tools for connecting and collaborating for the masses as well as for niche markets. Go2web20.net, a directory of Web 2.0 applications, lists over 3,400 online services with new ones being added each day. Because of the trending nature of social media applications, Kaplan & Haenlein (2010) took into account applications that may be forthcoming when developing a classification scheme to categorize the various types of social media. They relied on media research theories of social presence and media richness along with social process theories of self-presentation and self-disclosure to develop the classification matrix.

***Social presence and media richness.*** Short, Williams, and Christie (1976) developed the theory of social presence to explain the effect telecommunications media can have on communication. In their theory, social presence is defined as the degree of awareness (i.e., quality or state of being there) between two communicators using a communication medium. Simply put, Gunawardena and Zittle (1997) defined social presence as “the degree to which a person is perceived as a ‘real person’ in mediated communication” (p. 9). Different communication mediums mediate varying levels of social presence. If classified along a social presence continuum, face-to-face communication would be on one end with the highest degree of presence and text-based communication on the other end with the least. Short et al. (1976) described mediums with high degrees of social presence as being sociable, warm, and personal, whereas mediums with low degrees of social presence were seen as less personal.

Social presence can be influenced by the social psychological concepts of intimacy and immediacy. *Intimacy* refers to the “psychological distance that a communicator puts between himself or herself and the object of his/her communication” (Gunawardena & Zittle, 1997, p. 9). Therefore, interpersonal or face-to-face communication would entail high levels of intimacy whereas mediated communication media like texting and email would exhibit lower levels of intimacy. *Immediacy* refers to the way in which a medium transmits information. Synchronous forms of communication like talking in person or on the phone would be described as having a high degree of immediacy and asynchronous mediums like email or discussion forum posting would score lower on the immediacy scale. Communication mediums with high levels of intimacy and immediacy, then, would measure high in social presence. Short et al. (1976) argue that communicators have greater influence on each other’s behavior when levels of social presence are high.

According to the theory of media richness developed by Daft and Lengel (1984), a media is considered information rich by its capacity to provide new understanding and resolve ambiguity and uncertainty. They argued that “if the communication of an item of data, such as a wink, provides substantial new understanding, it would be considered rich. If the datum provides little understanding, it would be low in richness” (p. 196). Different forms of media possess varying levels of information richness and therefore can be more or less effective in resolving ambiguity or uncertainty. In Kaplan and Haenlein’s (2010) social media classification matrix, the first dimension classifies a medium based on its information richness and the level of social presence it allows. The second dimension classifies media based on its levels of self-presentation and self-disclosure.

***Self-presentation and self-disclosure.*** Goffman’s (1959) conceptualization of self-presentation states that people want to manage or control the impressions other people form of them. They can do this by regulating and controlling information in social interactions. He used a play as a metaphor to describe the process used to create desired impressions. People are actors within the social world who play various roles and create masks or personas for each of those roles in order to maintain the character they play. The motivations behind creating and managing impressions in the minds of others can be to gain material or social rewards and/or to avoid material or social punishments. For example, making a positive impression in the mind of an employer could lead to material reward in the form of a promotion or raise and making a positive impression in the minds of group can lead to the social reward of being accepted into the group and finding a sense of belonging. Another reason people may engage in self-presentation activities is to construct a particular image of themselves that is consistent with their identity



(Schlenkler, 1980). In the online world, the way people manage the impressions made of them is often through self-disclosure.

Self-disclosure is the communication of personal information such as thoughts, feelings, aspirations, goals, failures, successes, fears, dreams, likes, and dislikes (Altman & Taylor, 1973). The conscious or unconscious revelation of oneself is a critical step for developing intimacy and close relationships, but can also occur with strangers such as a therapist or doctor. Self-presentation and self-disclosure constitute the second dimension used to categorize social media in Kaplan and Haenlein's (2010) classification matrix.

Table 1

*Classification of Social Media by Social Presence/Media Richness and Self-Presentation/Self-Disclosure*

Self-presentation / Self-disclosure	Social presence / Media richness		
	Low	Medium	High
High	Blogs & microblogs	Social networking sites Discussion forums	Virtual social worlds
Low	Collaborative projects	Content communities	Virtual game worlds

*Note.* Adapted from "Users of the World, Unite! The Challenges and Opportunities of Social Media," by A. M. Kaplan and M. Haenlein, 2010, *Business Horizons*, 53, p. 62. Copyright 2009 by the Kelly School of Business, Indiana University.

**Social media categories.** Table 1 displays the combination of the dimensions of social presence/media richness and self-presentation/self-disclosure in a classification matrix for social media. Kaplan and Haenlein (2010) list six categories of social media applications within the matrix: collaborative projects, blogs, social networking sites, content communities, virtual game worlds, and virtual social worlds. Most social media applications can fit into one of these categories. For the purposes of this study, however, only five of these categories (collaborative

projects, blogs, social networking sites, content communities, and virtual social worlds) will be described in this section. Virtual game worlds will be excluded from this study because there is very little to no research in the literature on the use of this application for health-related purposes. In addition to Kaplan and Haenlein's (2010) categorization of social media, blogs will be expanded to include microblogs and a separate category for discussion forums will be created. Table 2 presents an overview of the six categories of social media that will be used to analyze caregiver online activity for support purposes.

Table 2

*Overview of Social Media Categories*

Category	Examples	Description
Collaborative projects	Wikipedia Pinterest	Sites and applications where people collaboratively build content. Wikis, such as Wikipedia, allow anyone to add and edit content. Social bookmarking tools such as Pinterest allow anyone to bookmark and share sites of interest.
Blogs and microblogs	Wordpress Blogger Twitter	Online publishing platforms that allow users to easily create and share content in the form of 'posts.' Posts containing text, photos, videos, and links are displayed in chronological order and can be 'tagged' with various topic tags. Tags make topical content searchable within the site and across multiple platforms through aggregators. Microblogs like Twitter follow a similar concept except the content posts are much shorter.
Discussion forums	BabyCenter Circle of Moms	Message boards that facilitate conversations in the form of posted messages. Users start conversations by posting a topic or "thread" and others respond by posting replies.
Social networking sites	Facebook PatientsLikeMe LinkedIn	Online services that enable people to connect by creating public profiles and inviting others to join their networks. Members can share ideas, media, posts, activities, events, and interests with people in their network as well as communicate through chat or direct messaging features.

(continued)

Category	Examples	Description
Content communities	YouTube Instagram Flickr	Online services that facilitate the sharing of media content between users and/or with the public. Most sites focus on a single media such as video (e.g., YouTube or Vimeo) or photos (e.g., Instagram or Flickr) or others such as art, graphics, memes, fictional stories, etc.
Virtual social worlds	Second Life	Computer-based simulated 3D environments where users appear in the form of avatars to interact with each other and engage with the virtual environment much like they would in real life.

**Communities of practice.** The various social media applications described in Table 2 provide a rich platform for communities to grow and develop online. They allow people to quickly and easily connect, form groups, and collaborate (Shirky, 2008), as well as harness collective intelligence or the *wisdom of the crowds* (Surowiecki, 2005). A community of practice is one type of community that technology has enabled to thrive in the online environment or *digital habitat* (Wenger et al., 2009). The central focus of these communities is the activity of learning together in the context of a particular practice or craft. The learning occurring in these contexts usually is not overt or formal, but a part of the human experience that involves identity creation, or as Wenger et al. (2009) state, “who we are, what we do, who we seek to connect with, and what we aspire to become” (p. 4).

In this study, parents and caregivers of children with Down syndrome who use the Internet to find support were examined as a community of practice. For simplicity, this group will be referred to as the Down syndrome community. Wenger et al. (2009) ascribe three fundamental dimensions to a community of practice: domain, practice, and community. Domain is a topic of interest or inquiry that provides an identity for a group of people who share it. For the Down syndrome community, the fundamental thing each member has in common is the challenge of caring for a child with Down syndrome. It is this challenge that brings them

together and provides an identity for the group. Therefore, the domain or the focus for collective learning for this community is the caregiver perspective on Down syndrome.

The ‘practice’ that this community shares is that of caring for a child with Down syndrome. Included in this practice are all the activities and techniques involved in caring for a child with physical and cognitive delays as well as possible medical conditions: coping with and accepting the diagnosis; understanding treatment options; managing appointments with doctors, specialists, and therapists; navigating the school system to get appropriate services; and dealing with the day-to-day challenges of caring for a child with special needs. Community members share and learn from each other’s day-to-day experiences with various aspects of their practice. For them, learning the practice of caring for a child with Down syndrome is learning “how to ‘live’ knowledge, not just acquiring it in the abstract” (Wenger et al., 2009, p.7).

The Down syndrome community can be considered on a macro scale to include all caregivers of children with Down syndrome who participate in any Down syndrome-related online activity, or on a more micro level by looking at smaller contained communities such as Facebook groups, Down syndrome blogs and bloggers, or discussion board groups. Social media facilitates the ‘community’ dimension by making it possible for people from all over the world who share this common practice to find each other, get to know each other in relevant ways, experience a sense of togetherness, learn with and from each other, and work together for various purposes (Wenger et al., 2009).

**Levels of participation.** Within communities of practice, there are various levels of member participation ranging from low to active participation. Some online communities have members in the thousands, but not all of them are regularly posting or contributing. Many in the community just read content posted by others; these members are commonly described as

‘lurkers.’ Lurkers engage in low-risk activities by observing but not directly participating (Preece, 2000). Lave & Wenger (1991) would interpret this type of engagement as *legitimate peripheral participation*, which Wenger et al. (2009) state is a “crucial process by which communities offer learning opportunities to those on the periphery” (p. 9). Although they may not actively participate within the community, lurkers often spend significant amounts of time in the community, learning its language and norms, identifying its key players, and sometimes becoming so familiar that they feel they belong to it (Nonnecke & Preece, 2001; Preece, Nonnecke, & Andrews, 2004). For the purposes of this study, participation levels within the Down syndrome community will be described using Preece’s (2000) online community roles:

- *Lurker* - Members who read or view content and observe what is going on but remain silent and do not participate.
- *Participant* - Members who contribute to the discussion by posting content (text, photos, videos, etc. and/or comments on content posted by others.
- *Moderator* - Members who help govern and direct activity within the community. Their role can be varied and may include duties such as answering questions about the group, managing the user list, organizing community events and activities, filtering messages, and helping people with general needs.

The ideals behind Web 2.0 and the social media applications that support them enable online communities for all kinds of topics and interests to form and grow. Social media use has extended into various spheres and industries and its impact can be seen in business and marketing, news and journalism, politics, music and entertainment, education, and, as will be expounded in this study, the area of health.

## Health 2.0

The Internet has become an increasingly popular source for health-related activities. In a 2010 Pew Research Center study, 80% of U.S. adult Internet users (or 59% of all adults) reported looking online for information on health topics. 34% of Internet users (or 25% of all adults) had read someone else's commentary about or experience with health or medical issues on an online news group, website, or blog. A survey of over 8,000 persons with multiple sclerosis (MS) found that although physicians were the most trusted source of health information, the Internet was the first source of health information for general health concerns (73.4%) and MS concerns (59.23%; Marrie, Salter, Tyry, Fox, & Cutter, 2013).

The Internet has been found to be a source of empowerment for patients suffering from various health issues and their caregivers by providing a sense of control in what can feel like a helpless and uncontrollable situation. They can use the Internet to get information, support themselves, and exert more control over their future (Preece, 1999; Stellefson et al., 2013). For some, getting in-depth knowledge of the condition helps them control their feelings of worry and anxiety and reduce their stress level (Gunderson, 2011). On the other hand, the abundance of information the Internet provides can also increase anxiety with information overload (Gunderson, 2011). Patients also need to be aware of the dangers of incorrect or misleading information (Preece, 1999).

Just as with general Internet use, health-related Internet activity has undergone a shift from a *read-only* consumption activity, to an interactive, collaborative, *read-write* enterprise that has been coined 'Health 2.0.' Where Health 1.0 could be described as users consuming content online, Health 2.0 describes the use of social media by members of the healthcare community to connect with each other for a variety of purposes. *Health prosumers* not only actively search for

health information (Sarasohn-Kahn, 2008), but also contribute to the community discourse by sharing opinions and experiences through activities such as reviews and ratings, blog posts, and forum messages (Doherty, 2008).

Hughes, Joshi, and Wareham (2008) suggest this definition for *Medicine 2.0*, which is used interchangeably Health 2.0:

Medicine 2.0 is the use of a specific set of Web tools (blogs, podcasts, tagging, search, wikis, etc.) by actors in health care including doctors, patients, and scientists, using principles of open source and generation of content by users, and the power of networks in order to personalize health care, collaborate, and promote health education. (p. 4)

Similarly, it has also been defined as “the use of social software and its ability to promote collaboration between patients, their caregivers, medical professionals, and other stakeholders in health” (Sarasohn-Kahn 2008, p. 2).

The emphasis that both of these definitions have placed on the different *actors* or *stakeholders* in health is significant. Through the use of social media, the hard line boundaries between these groups are being blurred (Doherty, 2008; Sarasohn-Kahn, 2008; Wicks, Vaughn, Massagli, & Heywood, 2011). Social media applications that facilitate connecting, sharing, and collaborating, as well as a general shift towards openness, has resulted in opportunities for collaboration between healthcare professionals, researchers, patients, and a mix of these three groups.

For example, PatientsLikeMe is a social networking site built to help patients (a) learn from others by comparing treatments, symptoms, and experiences of others with the same disease or condition; (b) connect with others to give and get support; and (c) track their health by charting their health over time and contributing to research that can help advance medicine

(PatientsLikeMe, n.d.). The amyotrophic lateral sclerosis (ALS) community on PatientsLikeMe, in particular, has received attention, not only for how members interact with each other by sharing health data and engaging in dialogues that can inform disease self-management (Frost & Massagli, 2008), but also for how self-reported data on use of experimental treatment drugs can be used by physicians, scientists, and experts (Wicks et al., 2011). The findings from the self-reported data were the same as subsequent randomized control trials, suggesting that patient reported data online may help accelerate various areas of research such as drug effectiveness evaluation and clinical discovery. More recently, PatientsLikeMe has partnered with a large biotechnology company that will utilize its online patient network to drive patient-centered research (PatientsLikeMe, 2014).

Another example of how Health 2.0 is blurring the lines between the different actors in health is in the changing role of healthcare professionals. Eysenbach (2007) coined the term *apomediation* to describe a shift in the role of the expert in this age of abundant information. Traditionally, healthcare professionals have stood in between patients and information as intermediaries or gatekeepers. With the rise of the Internet, patients were then able to bypass the intermediary and go directly to the information. However, with copious amounts of information came a need to discern what was trustworthy and credible. As a result, healthcare professionals have now become one of several methods a person can utilize to navigate the flood of information and find trustworthy sources (Eysenbach, 2007). No longer standing in-between the patient and a silo of information, healthcare professionals, *along with* peers, blogs, consumer ratings, and others, now stand beside (apomediate) to provide relevant and credible information. With access to a variety of sources for information, people now have the ability to choose who they turn to for various needs.



**Different sources for different needs.** A national survey on peer-to-peer healthcare activity among adults in the United States (Fox, 2011) found that people turned to different sources depending on the nature of the issue related to the medical condition or concern. Healthcare professionals like doctors and nurses mattered most for technical issues related to a health condition such as an accurate medical diagnosis, information about prescription drugs or alternative treatments, and recommendations for a doctor, specialist, or medical facility. Fellow patients, friends, and family mattered most for emotional support in dealing with a health issue and for quick remedies for everyday health issues. Both of these groups were found to be equally helpful in providing practical advice for coping with day-to-day health situations (Fox, 2011).

A number of studies on online support groups have found similar results on the different roles played by healthcare professionals and by peer support groups. Whereas healthcare professionals were turned to for technical issues, they were not a trusted source for emotional and empathic support. After analyzing content posted on an online support community, Preece (1999) concluded that “physicians can provide the facts, but other patients can tell you what it really feels like and what to expect next, in a way that only someone with personal experience can” (p. 63). In a similar sentiment, a primary caregiver of a child with special needs stated that she joined an Internet parent support group because “most professionals are not going to tell you the down and dirty truth you are going to get from other parents who live this every day. Probably because they could never imagine what it is like” (Baum, 2004, p. 386).

This study examined the role of the peer support community that is accessed through social media applications. In order to understand how the Internet mediates social support for people experiencing medical issues or caring for others with medical conditions, the concept of social support will first be discussed.

## Social Support

The concept of social support is broad and complex with no single definition that encompasses the varied social interactions that are affiliated with it. Definitions of social support are often situated in the context in which they are studied (Williams, Barclay, & Schmied, 2004). Cobb's (1976) definition describes social support in the context of crisis and change as "information leading the subject to believe that he is cared for and loved, esteemed, and a member of a network of mutual obligation" (p. 300). House's (1981) definition is derived from existing social support literature and is more general in nature:

Both scientific experts and relatively uneducated laypersons agree that social support is an interpersonal transaction involving one or more of the following: (1) emotional concern (liking, love, empathy), (2) instrumental aid (goods or services), (3) information (about the environment), or (4) appraisal (information relevant to self-evaluation). (p. 39)

Weiss (1974) incorporated major elements from key conceptualizations of social support in the literature (see Cutrona & Russell, 1987) to develop six social functions that can be obtained from interpersonal relationships: guidance, reliable alliance, reassurance of worth, opportunity for nurturance, attachment, and social integration. *Guidance* can come in the form of advice or information and can also be described as instrumental or informational support. *Reliable alliance* is the assurance that others can be counted upon for tangible assistance or material support. *Reassurance of worth*, also known as esteem support, is the recognition of one's competence, skills, and value by others. *Opportunity for nurturance* deals with feelings of responsibility for the well-being of another. *Attachment*, or emotional support, describes emotional closeness that produces a sense of security. *Social integration* is a sense of belonging

to a group that shares similar interests, concerns, or recreational activities. This is also known as network or belonging support (Cutrona & Russell, 1987; Weiss, 1974).

***Social support impact on health.*** The way functions of social support impacts health and well-being has been extensively studied and falls into two categories. The *stress buffering* model is the dominant perspective that views social support as a means of buffering and protecting an individual from the negative effects of stress, crisis, or change (Cobb, 1976; Cohen & Syme, 1985; Kaplan, Cassel, & Gore, 1997; Stewart, 1990). Supportive actions can moderate stress in times of crisis and change and facilitate coping and adaptation. The related stress-support matching hypothesis posits that social support is effective for helping individuals cope and reducing the effects of a stressor *if* the form of assistance matches the demands of the stressor (Cohen & McKay, 1984; Cutrona & Russell, 1990).

Another popular perspective is the *main-effect* or *direct-effect model*, which hypothesizes that social support directly impacts the health and well-being of an individual by meeting basic social needs (Pilisuk, 1982; Thoits, 1982). Unlike the buffering model where social support is mostly beneficial in times of crisis and stress, the main-effect model views social support as a positive influence on health regardless of stress. It is the perception of the availability of support or being part of a social network that enhances health and well-being (Cohen & Syme, 1985).

Depending on the subject of measurement, there is evidence in the literature that supports both the buffering model and the main-effect model's impact on health and well-being (Cohen & Wills, 1985; Thoits, 1995). When the subject's availability of support resources for stressful events is measured, the buffering effect of social support is present. When the subject's integration within a social network is measured, direct effect is found to occur (Cohen & Wills, 1985). Studies have found that "perceived emotional support is associated directly with better

physical and mental health and usually buffers the damaging mental and physical health impacts of major life events and chronic strain” (Thoits, 1995, p. 64).

***Structural and functional characteristics.*** Researchers have approached the study of social support from two perspectives: structural and functional. Structural measures describe the existence of relationships and assess the objective characteristics of social networks such as number of ties, density of connections, and relationships status (Cohen & Syme, 1985; Cohen & Wills, 1985). Functional measures of social support look at the role relationships and networks serve such as Weiss’ (1974) six social functions described earlier. They assess whether interpersonal interactions provide the distressed individual with the assistance needed (e.g. feelings of being cared for and esteemed, a sense of belonging, information, material aid, etc.) as well as the extent to which those relationships may provide particular support functions (Cohen & Wills, 1985). This study utilized the functional approach to assess perceived social support provided by an online support community. Specifically, measured four of Weiss’ (1974) social functions that can be gratified through online social support mediums: guidance, opportunity for nurturance, attachment, and social integration.

### **Online Social Support**

Combining social media with social support results in a significant sub-section of Health 2.0 referred to as *online social support*. Broadly speaking, online social support can be defined as support gained through online interactions and exchanged with people who are, for the most part, unseen and unknown (LaCoursiere, 2001). Traditionally, social support from peers and those who share similar experiences are found in local face-to-face support groups. Although those groups provide valuable services in their own right, there are certain advantages to using the

online medium to seek support such as: convenience and accessibility, anonymity, and diversity of experience.

For caregivers working around a child's schedule and needs, going to a physical location at pre-designated times can be difficult, if not impossible. This is also the case for people who are home-bound due to medical reasons or lack of transportation (Coulson & Knibb, 2007; Sharf, 1997; Weinberg et al., 1995; Wright, 2000). The asynchronous nature of most online support applications allow users to participate when they want and also catch up if they were not able to participate for a period of time (Weinberg et al., 1995). The time and location independence of Internet communications, as well as the ease and speed of accessing online support from home especially in light of work and family commitments, makes online support services a popular option over face-to-face support groups (Leimeister et al., 2008).

Anonymity in online support communities enables people to safely disclose information about themselves without fear of stigmatization (Wright, 2000; Wright & Bell, 2003). It also provides opportunities for those who are not comfortable in group settings or who do not enjoy being part of a formal group to access support without going to face-to-face meetings (Weinberg et al., 1995). Online communication has been found to increase openness because of greater anonymity (Kiesler, Siegel, & McGuire, 1984).

Although local support groups bring together small groups of people who share similar conditions, the experience or the issues may not be same. However, with online support communities, instead of a group of 5-20 people, users can connect to thousands of people and find others with the same problem or issue (Preece, 1999; Sharf, 1997; Wright, 2000; Wright, 2002). In addition to similarity of experiences, online communities also provide opportunities to interact with a more diverse group of members with a range of experience than cannot be found

in traditional local support groups (Wright, 2002). For rare conditions, there may not even be a support group available. In a Pew Research Center study on peer-to-peer healthcare, one mother of a child with a rare condition writes this about the support she found online:

When a disease is so rare and there are no folks in your town, and few in your state who are going through what you are going through, you need a support group that encompasses people from all over the world. Getting to know people through the disorder has been an amazing experience and has created incredibly wonderful friendships and ties. (Fox, 2011, p. 11)

Social media plays a significant role in online social support. Merolli, Gray, and Martin-Sanchez (2013) studied the affordances social media provides for individuals' self-management of chronic diseases. Affordances are the potential uses of an object. More than the specific features of social media platforms, they were interested in 'how' social media use influenced outcomes such as engagement or participation, social interactions, effect on disease-specific knowledge, psychosocial impacts, and physical condition impacts. They analyzed 19 studies and identified the following affordances:

- *Identity* - social media affords chronic disease sufferers more choice and control of the public persona they present and how much of themselves and their condition they share. Anonymity and avatars allow self-conscious patients to interact without fear of judgment.
- *Flexibility* - Social media provides sufferers choice and freedom about when and where they interact.
- *Structure* - Social media affords sufferers with participation structures that allow various types of interactions such as connecting, sharing, and collaborating. Social

media can act as a guide or filter (apomediary) to relevant and accurate information for self-management.

- *Narration* - Social media provides sufferers with opportunities to tell their story, express and manage emotions, and share information.
- *Adaptation* - As information, support, and overall management needs change over time, social media provides sufferers the ability to adapt self-management behavior.

**Uses and gratifications examination of social support.** In the context of this study, users have a variety of social media applications to satisfy their support needs. Even within online social support, there are a variety of applications that enable caregivers to connect with others to find information and support as described in Table 2. Prior studies on online social support generally focus on earlier social platforms such as online support groups and discussion/message boards (Merolli et al., 2013). There are, however, a growing number of studies on the use of other social media applications such as blogs and social networking sites for health-related social support (Weiss & Campion, 2007). The use of social media applications for support purposes can result in a variety of benefits or gratifications that can be categorized under four of Weiss' (1974) social support provisions: guidance, attachment, social integration, and opportunity for nurturance. For this study, these gratifications were renamed (respectively): informational support, emotional support, belonging support, and active support.

***Informational support.*** Ziebland & Wyke (2012) performed a conceptual review of the literature exploring the health effects of access to and use of online patients' experience. They identified information sharing as one of the key domains through which online patients' experience could affect health. From the literature, they found that the sharing of people's experience was a type of information that may: help allay fears and boost confidence; allow

patients to compare symptoms and their effects with their own experience, which could suggest or confirm a doctor's diagnoses; provide contextual information that may help people understand what may happen; help change perception about the illness by hearing about how others have coped; provide coping strategies for problems encountered in day-to-day life; and be a source of information for decision-making.

Informational support can be a source of empowerment for patients and caregivers (Attard & Coulson, 2012; Høybye et al., 2005; van Uden-Kraan et al., 2008). Women in an online breast cancer community reported feeling empowered by the knowledge they gained from the community about their disease and how to live with it (Høybye et al., 2005). Cancer patients and their caregivers who read cancer blogs reported feeling empowered by the information they received, which they did not feel through traditional health care providers (Chung & Kim, 2008).

***Emotional support.*** Emotional support was another key domain in Ziebland & Wyke's (2012) literature review. The possible impacts of feeling supported included: the ability to 'normalize' one's experience; feelings of hope and reassurance concerning what the future may hold; greater feeling of control and confidence about managing the situation; inducing feelings of compassion; and gaining a different perspective. In a study examining the use of blogs by cancer patients, an online survey of 113 respondents found that blogging activity was most helpful for emotion management along with information sharing (Chung & Kim, 2008). The socially interactive features of blogs enable patients to express frustrations and cope with cancer situations.

Empathy is a significant characteristic of online support communications. In a study of 100 online communities, empathic communication was strongest in the patient and emotional support communities (Preece, 1999). There are various examples from online social support



literature of empathic communication. In an analysis of 500 posts written by 251 users on an online medical support group discussion board, 45% of the posts were empathic messages (Preece, 1999). The other posts were personal narratives (32%) and questions or answers (17%). Numerous responses on an Irritable Bowel Syndrome message board expressed empathy, support, and reciprocate emotion as well as messages of hope and encouragement (Coulson, 2005). In a study of a Parkinson's disease online support group, members reported the community to be understanding and empathic and a valuable source of emotional support. For example, two message posts show how members expressed understanding and empathy: "No one understands your situation unless it has or they are [sic] living with the same problem" and "I am worried about you. I have been there myself and know how difficult it is" (Attard & Coulson, 2012, p. 502).

Also included in emotional support is the ability to express honest feelings without fear of repercussions. Chung & Kim (2008) found that cancer blogs were used as an outlet to express frustration dealing with issues. The Irritable Bowel Syndrome message boards were an outlet for venting frustration and the responses by members provided validation for those feelings and views (Coulson, 2005). In a study of an online support community for parents of children with rare genetic conditions, one parent who was interviewed felt that the community was a place where she could share her thoughts and vent her emotions without risking negative consequences and said this:

I have told our story many times. We all have our vicissitudes, and sometimes I just have to let it all out, positive as well as negative thoughts and feelings. In addition, you get a sort of temperature check, and sometimes I receive positive and other times negative

responses. These responses allow me to organise my thoughts and help me think about which step to take next. (Gunderson, 2011, p. 90)

***Belonging support.*** Several examples in online social support literature show how online support communities help reduce feelings of isolation that many patients and caregivers experience. Members of an online breast cancer community felt that the mailing list broke down the social isolation created by their disease and entered them into a new community (Høybye et al., 2005). Food allergy online support group members reported feeling alone in their suffering and not able to even draw upon support from friends and family; however, participation in the online support group reduced feelings of social isolation (Coulson & Knibb, 2007). Ziebland and Wyke's (2012) review of the literature of the online sharing of patients' experience reported that feeling supported reduced feelings of isolation and produced a sense of belonging.

***Active support.*** Active support refers to the support received when helping others (Weiss, 1974). Sharing one's past experience is a way to reach out to others and can result in raised self-esteem and finding meaning in one's own experience (Høybye et al., 2005). In a survey of primary caregivers of children with special health care needs on their use of Internet parent support groups, seeking the opportunity to help others was reported as the strongest, most frequent motivator for participating in a support group among emotion-focused coping strategies (Baum, 2004). For parents of children with rare genetic conditions, contributing to the work of the support group and raising money for research were considered positive or redemptive effects of their child's genetic diagnosis (McCallister et al., 2007).

Studies have shown the impact of online social support for people with a variety of health and medical conditions. This study focuses on online social support in the context of caregivers of children with Down syndrome. In order to understand the actions and motivations of this

group, it is important to understand the support needs of caregivers of individuals with special needs related to genetic conditions.

### **Caregiver Support Needs**

A national survey by the Pew Research Center found that 36 percent of U.S. adults care for an adult or multiple adults and 8 percent of U.S. adults care for a child with medical, behavioral, or other condition or disability (Fox, Duggan, & Purcell, 2013). The study showed that caregivers were heavy technology users and, compared to other Internet users, were more likely to participate in the following activities:

- Gather health information online, particularly about medical problems, treatments, and drugs
- Go online specifically to try to figure out what condition they or someone else might have
- Consult online reviews about drugs and other treatments
- Track their weight, diet, or exercise routine
- Read online about someone else's personal health experience
- Go online to find others with similar health concerns

When asked about the specific impact of the Internet:

- 59% of caregivers with Internet access say that online resources have been helpful to their ability to *provide care and support for the person in their care*.
- 52% of caregivers with Internet access say that online resources have been helpful to their ability to *cope with the stress of being a caregiver*.

Parents and caregivers of children with Down syndrome were selected as the focus of this study because of their strong and active online presence. Though there are several professional

organizations that provide informational services about Down syndrome, there are numerous ‘bottom-up’ communities set up by caregivers themselves to help support one another (Burrows, Nettleton, Pleace, Loader, & Muncer, 2000). Multiple Facebook groups for caregivers of children with Down syndrome have over 5,000 members, community groups and forums have over 1,000 participants, and the researcher has gathered a growing list of over 300 blogs focused on raising a child with Down syndrome. This group’s utilization of social media applications for social support purposes made it a prime population for this research.

**Down syndrome and rare genetic conditions.** Every year, it is estimated that 7.9 million children worldwide are born with a serious birth defect of genetic or partially genetic origins that can be lethal or can cause lifelong disability (Christianson, Howson, & Modell, 2006). In the March of Dimes Global Report on Birth Defects (2006), data show that 3.3 million children under five years of age die from birth defects each year, and an estimated 3.2 million of those who survive may experience mental, physical, auditory, or visual disability.

Every year, one in every 691 babies in the United States is born with Down syndrome, a genetic condition that occurs when an individual has a full or partial extra copy of chromosome 21, making their total chromosomal count 47 instead of the typical 46 (National Down Syndrome Society [NDSS], n.d.). Down syndrome is the most commonly occurring genetic disorder and it is estimated that there are more than 400,000 people living in the United States with the condition (NDSS, n.d.).

Most individuals with Down syndrome share characteristic features including shorter stature, upward slanted (almond shaped) eyes, a large tongue, a single crease on the palm of their hands, and poor muscle tone. Although the range varies, people with Down syndrome experience physical and cognitive developmental delays and have an increased risk for certain medical

conditions such as congenital heart defects, respiratory and hearing problems, Alzheimer's disease, childhood leukemia, gastrointestinal issues, and thyroid conditions (Centers for Disease Control and Prevention [CDC], 2013; GeneFacts, n.d.; Sherman, et al., 2007.).

Although there are prenatal tests that can screen for a fetus with Down syndrome, the majority of parents receive the diagnosis shortly after childbirth (Skotko, 2005). Doctors are usually able to make an initial diagnosis based on the infant's physical characteristics and then will order a genetic test to confirm the presence of the extra chromosome (CDC, 2013). For parents, receiving the diagnosis often comes as a shock and is especially difficult since they are already in an emotional and vulnerable state from the labor and delivery process (Gunderson, 2011; Selkowitz, 2008; Skotko, 2005). Because the diagnosis is made so shortly after birth, parents do not have a chance to get to know their child as an individual before he or she is labeled with a syndrome (Selkowitz, 2008).

Feelings of fear and anxiety can be exacerbated when healthcare professionals provide parents with a bleak outlook and point out only the negative aspects of the condition (Choi, Lee, & Yoo, 2011; Skotko, 2005; Skotko, et al., 2009). In a study of parents of children with rare genetic conditions, some parents reported feeling hopeless because of the doctor's pessimistic view regarding their child's prospects and prognosis. They also felt that the information they received from the doctor was insufficient (Gunderson, 2011).

Parents of children diagnosed with Down syndrome and other rare genetic conditions experience high levels of emotional stress (Gunderson, 2011; Mullins, 1987; Singer & Irvin, 1989). One parent gave this example about the stress experienced when they received their child's diagnosis of a rare genetic condition:

The doctor told us he had . . . syndrome, and then the consultation was over. Then we sat there and did not know what to do. Even though it was a relief to have a confirmed diagnosis, it was also terrible to have your worst suspicions confirmed. Moreover, not knowing what . . . syndrome implied . . . the baby was taken care of, but no one thought about us – and I had a mental crisis and my husband withdrew and did not want to talk about it. It was a tough time. (Gunderson, 2011, p. 86)

In a study exploring the emotional effects of genetic diseases on families, parents reported feelings of anxiety, anger, uncertainty, sadness, and grief. They also reported feelings of guilt for passing a genetic condition or a faulty gene to their children, which is unique from the experiences of parents of children with non-hereditary diseases (McCallister et al., 2007). Parents often mourn the loss of the healthy child they had expected or desired. They have to readjust their thinking to learn to live with their child's condition as well as revise their earlier dreams and expectations (Krahn, 1993). During this vulnerable time, they may also be required to deal with and manage their child's complex medical needs (Abery, 2006; Choi et al., 2011; Gunderson, 2011; Skotko, 2005).

Families of children with special needs experience high levels of caretaking demands. They need to continually monitor their child's health status as well as maintain multiple health, therapy, and educational appointments (Krahn, 1993; Mullins, 1987; Singer & Irvin, 1989). A significant stressor for parents is not knowing how the condition will impact their child's future prospects or what the probable medical, intellectual, or social consequences of the condition may be (Gunderson, 2011; McCallister et al., 2007).

Several studies note various coping mechanisms utilized by parents once they receive a diagnosis of a genetic condition. These mechanisms can be categorized into two approaches:

*avoidance-based* strategies (also noted as *palliative* or *emotion-based* strategies) and *problem-solving* or *cognitive* strategies (Atkinson et al., 1995; Bingham, Correa, & Huber, 2012; Glidden, Billings, & Jobe, 2006; Glidden & Natcher, 2009). Avoidance-based strategies include denial, wishful thinking, self-blame, asking “why,” and minimizing the situation (Abery, 2006; Bingham et al., 2012). In one study of parents of children with developmental delays, avoidance-based strategies were associated with increased depression and poorer subjective well-being (Glidden et al., 2006).

Parents coping with their children’s developmental disabilities, however, more often use problem-solving coping strategies which include: seeking information; emotional, religious, or professional support; reframing the situation or positive reappraisal of the situation; and accepting responsibility (Bingham et al., 2012, Glidden et al., 2006). This study focuses on the use of problem-solving coping strategies, specifically, seeking informational and emotional support, by parents and caregivers of children with Down syndrome.

Siklos and Kearns (2006) studied the perceptions of needs of parents of children with developmental disorders and whether they felt those needs were being met. Fifty-six parents of children with autism and thirty-two parents of children with Down syndrome completed a modified Family Needs Questionnaire. These parents indicated the following social support needs as being important to them:

- The need to be well-educated about my child’s disorder in order to be an effective decision-maker regarding the needs of my child
- The need for help dealing with my fears about my child’s future
- The need for help in remaining hopeful about my child’s future
- The need to be told why my child acts in ways that are different, difficult, or unusual

- The need to discuss feelings about my child with a parent who has a child with the same disorder
- The need to have my questions answered honestly

The literature shows that the need for or significance of social support for caregivers of children with special needs change over the life span of the child (Krahn, 1993; Long, Katz, & Pokorni, 1989; Williams 2004). In a short-term, longitudinal study of support to families with chronically ill young children, Long et al. (1989) found that families' needs for emotional support and caregiving information were initially high and then diminished over the baby's first 18 months. Support needs of parents of children with rare genetic conditions progressed from information about the condition in the first stage of coping, to advice and guidance about treatment and day-to-day care as well as information to discuss with healthcare providers, and finally to social support from others with similar experiences (Gunderson, 2011). In Plumridge, Metcalfe, Coad, and Gill's (2012) study of families affected by genetic conditions, some families moved away from psychosocial support groups after they felt they had exhausted its benefits and moved to raising funds or awareness about the condition, which they felt was more proactive.

## **Summary**

The way people interact with each other through the World Wide Web dramatically shifted with the emergence of Web 2.0. Tools and applications called social media enabled people to connect, collaborate, create, and contribute in new ways that blurred the boundaries between professionals and amateurs. Web 2.0's influence in the world of health care and management, or Health 2.0, has opened doors for people with medical issues and their caregivers to find others like them who can help provide social support for what can be incredibly stressful situations.



## **Chapter 3. Research Design**

### **Overview of Purpose**

The purpose of this mixed methods explanatory sequential study was to utilize a uses and gratifications framework to examine how caregivers of children with Down syndrome use social media to access social support. In the first phase, quantitative data was collected on respondents' choice of social media applications, motivations, perceived social support outcomes, and background information. The second phase used responses from the first phase to select specific social media sites to examine using a thematic content analysis.

#### **Research questions.**

RQ1. How do caregivers use social media for social support purposes?

RQ2. What are caregivers' primary motivations for using social media for social support purposes?

RQ3. How does the use of social media mediate caregivers' perception of social support outcomes?

### **Research Design**

In the first phase of this study, a cross-sectional survey research design quantitatively explored the relationships between caregivers' use of social media applications, their motivations for use, their perception of social support outcomes, and their background. Survey design facilitates data collection from a large sample, which can then provide insight into the activities, perceptions, and attributes of a larger population (Fowler, 2009). The survey method is relatively inexpensive, especially when administered online, and is a quick method of data collection. This study employed an online questionnaire that was sent out as a link in an email to members of a Down syndrome organization and to active Down syndrome bloggers. The link to the

questionnaire was also posted on various Down syndrome-related social media sites. Survey responses were accepted for a total period of four weeks.

In the second phase, a thematic content and feature analysis of social media sites was performed. The analysis looked for patterns and shared characteristics among popular sites used by respondents for Down syndrome-related purposes. Content analysis is a widely used research method for the objective, systematic, and quantitative examination of communication content (Berelson, 1952). According to Krippendorff (2004), content analysis can be advantageous because it is unobtrusive, unstructured, context sensitive, and can cope with large volumes of data. It is also a relatively simple and economical technique since the data is readily available.

### **Sample**

The theoretical population investigated in this study was parents or caregivers of children with Down syndrome who use the Internet. Although the size of this population is undeterminable, the National Down Syndrome Society estimates that one in every 691 babies in the United States is born with Down syndrome and that over 400,000 people in the United States are living with the condition. Using a voluntary sampling method, subjects were self-identified parents or caregivers of children with Down syndrome who go online to get information and support and who opt-in to participate in an online questionnaire. This non-probability sampling approach was appropriate because this was not a known population, which makes a random sample impossible to construct.

Participants were recruited from the membership of a Down syndrome organization as well as various Down syndrome-related social media sites. These sites were found through online searches for Down syndrome-related social media sites and communities. In a snowball effect, links to other sites helped to grow the site list. Sites were selected based on high levels of

membership, readership, and activity. The researcher obtained permission from site authors, moderators, and facilitators to solicit participation from its members or readers. The recruitment message included brief information about the study and the researcher and a link to the online survey.

Data collected from the online survey responses provided demographic and background information about the sample (see Table 3). Survey responses showed that all of the respondents in the dataset ( $n = 100$ ) were parents of children with Down syndrome. Half of the respondents (51%) were in their 30s and 38% were in their 40s. Eight parents were under 30 years old and three parents were 50 years old or older. The ages of the children under their care ranged from newborns to 18 years old. More than half of the children (55%) were under the age of 3.

Questions about access to health insurance were used to gain general demographic information about the sample. Nearly three fourths (74%) of the respondents had private health insurance, 22% had public health insurance, and 4% had no health insurance. According to U.S. Census Bureau data, “those with lower household income were likely to have coverage through government health insurance programs compared with people with higher household income, who tend to have private coverage” (Smith and Medalia, 2014, p. 8). In terms of location, 33% indicated living in cities, 47% in suburbs, and 20% in rural areas.

Table 3

*Summary of Responses to Background Questions*

Answer Options	Response Count	Response %
Q11. What is your relationship to the individual with Down syndrome? ( $n = 100$ )		
Parent	100	100%
		(continued)

Answer Options	Response Count	Response %
Q12. What is the age of the individual with Down syndrome under your care? ( <i>n</i> = 100)		
Less than 1 year	20	20%
1-2 years	35	35%
3-4 years	21	21%
5-12 years	20	20%
13 years or older	4	4%
Q13. How long have you been a caregiver for an individual with Down syndrome? ( <i>n</i> = 100)		
Less than 1 year	21	21%
1-2 years	34	34%
3-4 years	20	20%
5-12 years	20	20%
13 years or longer	5	5%
Q14. How old are you? ( <i>n</i> = 100)		
18-29 years	8	8%
30-39 years	51	51%
40-49 years	38	38%
50 years or older	3	3%
Q15. What type of access do you have to health services? ( <i>n</i> = 100)		
Private insurance (usually employment-based)	74	74%
Public insurance (e.g. Medicaid)	22	22%
No insurance	4	4%
Q16. What type of access does the individual with Down syndrome in your care have to health services? ( <i>n</i> = 99)		
Private insurance (usually employment-based)	62	63%
Public insurance (e.g. Medicaid)	35	35%
No insurance	2	2%
Q17. Where do you live? ( <i>n</i> = 98)		
City	32	33%
Suburb	46	47%
Rural	20	20%

## **Instrumentation and Data Collection**

**Phase I: Online survey.** The survey was built in and accessed through Qualtrics, an online survey software. Administering an online survey was an appropriate method of data collection since the subjects in the sample were caregivers who were already online and using social media. Upon completion of the 4-week window for survey completion, answers were downloaded, coded, and analyzed. The survey consisted of 17 questions that were divided into three sections. The first section provided introductory text explaining the purpose of the study, assurance of participant confidentiality, and contact information for the researcher. Respondents were then asked for their consent to participate in the survey. Those who disagreed to the consent were directed to the end of the survey and those who agreed continued on to the next section. The second section asked respondents about their social media use, motivations for use, and perceptions of social support. The last section contained questions about the respondent's background and demographic information.

***Social media engagement.*** Question 1 asked respondents to list the URLs of up to five websites they accessed to get Down syndrome-related information and support. Question 2 asked respondents to then choose the *one* website they engaged with the most and to state its name or URL in a textbox. The response in the textbox was then automatically piped into questions 3 through 8, which pertained specifically to this site. Questions 3 and 4 asked respondents about the frequency and length of their engagement with the site. Question 5 asked respondents to indicate how often they participated in various activities on the site:

1. I read or view content posted by others.
2. I comment on or reply to content posted by others.
3. I post my own content (text, photos, videos, audio, etc.).

4. I help organize, moderate, or lead the group.

These activities correspond with roles commonly found in online communities (Preece, 2000). When reading or viewing content is the primary activity, the user is often called a *lurker*. A *participant* is more active and engages in activities 2 and 3 in addition to the first activity. The most involved of the four activities is the last one and is performed by the community *moderator*.

***Social support gratifications sought.*** With the site listed on question 2 still in mind, question 6 asked respondents to indicate their motivation for using the site. Seventeen possible reasons for visiting the site were listed and respondents were asked to indicate on a 4-point scale (ranging from strongly agree to strongly disagree) the degree to which each of the statements reflected their motivation for visiting the site. A *not applicable* response was also available for each statement. This measurement looking at motivations for utilizing social media was created specifically for this study. The 17 motivation statements were derived from a number of studies from social support and uses and gratification literature (Baum, 2004; Cutrona & Russell, 1987; Pappacharisi & Rubin, 2000; Preece, 2000) and crafted for this specific audience. The statements can be grouped by the four categories of Weiss' (1974) social support provisions or gratifications as described in the previous chapter:

- Informational support (guidance and information)
- Emotional support (emotional closeness providing a sense of security)
- Belonging support (the sense of belonging to a group similar to oneself)
- Active support (the sense that one is needed by others)

***Social support gratifications obtained.*** For question 7, the Social Provisions Scale (Cutrona & Russell, 1987) was adapted and used to measure perceived social support obtained

from the respondents' use of the specific site listed in question 2. The researcher obtained permission for the adaptation and use of the instrument through communication with Daniel W. Russell, Ph.D. Extensive research supports the reliability and validity of the Social Provisions Scale (Cutrona & Russell, 1987; Mancini & Blieszner, 1992; Russell, Altmaier, & Van Velzen, 1987).

The original scale assesses the six relational provisions identified by Weiss (1974). From those six, the four provisions related to online social support that correspond to the motivations in the question 6 were used for this study. The original scale uses two positively worded statements and two negatively worded statements to assess each provision. For example, a positive statement for guidance or informational support would be, "There is someone I can talk to about important decisions in my life." and a negative statement would be, "There is no I can turn to for guidance in times of stress." For this study, only the positively worded statements were used in order to keep the survey length short. This 8 question modified scale has strong concurrent validity with the original scale and high internal consistency (Caron, 2013). The measurement asked respondents to indicate on a 4-point scale (ranging from strongly agree to strongly disagree) the degree to which each of the statements described their current interactions with people on the specific site. A *not applicable* response was also available for each statement.

***Open-ended questions.*** The last part of this section asked respondents to answer three open-ended questions. The first one, question 8, asked respondents to state their reasons for engaging with the specific site they listed on question 2 more than other online resources for Down syndrome-related information and support. Question 9 asked respondents how they determined the trustworthiness of the content they find online, especially in terms of accuracy, credibility, and relevance. The last question of this section, asked respondents if they had

attended face-to-face Down syndrome support groups, and if so, to list the differences between face-to-face support communities and online support communities.

***Respondent background.*** The last section of the survey used collected information on the background of the respondents and the children in their care. This included questions about their relationship to the individual with Down syndrome, the age of the individual with Down syndrome under their care, and how long they had been providing care to the individual. Respondents were also asked about the type of access to health services they, and the individual in their care, carried: private insurance, public insurance, or no insurance. These responses can provide general demographic insight such as household income (Smith & Medalia, 2014). Additional demographic questions such as age and location were also asked.

**Phase II: Content analysis.** In question 1 of the online survey, respondents were asked to list up to five websites they frequented for Down syndrome-related support and information. This list was aggregated and the sites that were popular were placed in a list of potential sites for analysis. Two sites representing the most frequently mentioned types of sites were then analyzed according to a rubric looking for patterns and trends from a technical/technological perspective and from a content perspective.

## **Data Analysis**

**Phase I: Online survey.** After the four-week window for participation in the online questionnaire was complete, the data was downloaded, coded, and analyzed. The dataset used for analysis contained only the data from respondents who completed 50% or more of the survey. Several types of data were extracted from the responses: website URLs from questions 1 and 2, quantitative data, and qualitative data from the open-ended questions (8-10). Each type of data required different forms of analyses.



**Website URLs.** The URLs from question 1 were aggregated into a single list. Because of the many variations of responses, even for the same site (site title, site URL, site description, etc.), a master list was created with the name and URL of each site from the responses. The individual responses on the original aggregated list were then changed to show the standard names from the master list. The list was then sorted alphabetically and a count was taken for each of the different sites. The responses from question 2 went through the same process. Both of these lists were then used to come up with the list of potential sites for the content analysis section of the study.

**Quantitative Data.** Quantitative responses were downloaded, coded, and imported into SPSS, a statistical analysis software package. Before this step, however, the responses from several questions had to be coded and/or converted in order to perform statistical analyses. For question 2, the websites listed in the responses were placed into Kaplan and Haenlein's (2010) social media categories and coded accordingly:

- Collaborative Projects (e.g. Wikipedia, Pinterest)
- Blogs & Microblogs (e.g. Wordpress, Blogger, Twitter)
- Discussion Forums (e.g. BabyCenter, Circle of Moms)
- Social Networking Sites (e.g. Facebook, Google+)
- Content Communities (e.g. YouTube, Instagram, Flickr)
- Virtual Social Worlds (e.g. Second Life)
- Other

Questions 12 and 13 asked about the age of the child under care and the length of time the respondent has acted as the caregiver respectively. An open text box was used to record the responses instead of a set scale in order to obtain more meaningful data. As a result, the

responses came in several formats (months and years) and a variety of different abbreviations were used. These responses were standardized and then grouped into age ranges that made sense based on the responses. Once all of the data was prepared, it was entered into SPSS for analysis. Descriptive statistics (frequency, mean, standard deviation) was generated for each of the questions as applicable. Two-tailed bivariate correlations were also performed using the data. For the Social Provisions Scale in question 7, in addition to descriptive statistical analysis, the responses were scored using the 4-point scale, which was then summed to get a total score.

***Qualitative Data.*** Each of the three open-ended questions (Q8-10) in the online survey went through an iterative process to develop the coding schema. Based on the literature, several general coding categories were developed based on the nature of the question and used as starting off points. In the first iteration of the coding process, keywords and topics were pulled out during the initial read through of the responses. The list was then refined into categories and frequency counts were generated for the categories mentioned in the responses. The initial count revealed some overlap of categories as well as sparse number of responses for certain categories. For the second iteration, categories were collapsed into more general themes and then recounted. Question 8 went from having 19 categories to just 9; question 9 went from 9 categories to 7; and questions 10 went from 12 categories to 7.

**Phase II: Content analysis.** From the analysis of question 1, the most frequently cited website categories were identified. The first category of websites was Facebook groups and the second was BabyCenter groups. One group from each of the two categories was selected for analysis. The content on these sites is very dynamic so capturing stable data required taking a snapshot of each site at a specific time. For the Facebook group, all of the posts published on a specific date were used for analysis. For the BabyCenter group, because it had a much lower

volume of activity compared to Facebook, all of the posts from a period of 20 days were used. The same method as the open-ended questions in the online survey was used to generate the coding schema for these two sites. In addition to a keyword/topical analysis of the content, the sites features and design were analyzed using a rubric looking at (adapted from Weiss & Campion, 2007):

- Social media classification
- Access
- Moderation structure
- Participation structure
- Content structure
- Content feedback
- Identity management

### **Validity and Reliability**

The survey tool was pilot tested by colleagues including those who are familiar with the online special needs communities and those who are not. The survey was also reviewed by active participants within the online Down syndrome community (group moderators, prolific bloggers, etc.). Updates were made to the survey based on feedback from colleagues and community leaders.

### **Ethical Considerations**

There was minimal risk for human subjects in this study. At most, respondents had an imposition placed on their time. For some respondents, there was the possibility of emotional discomfort when thinking about their child's diagnosis. If this was the case, respondents were instructed to stop the survey at any time. The identity of survey respondents was completely

anonymous and no identifying information was taken for the content analysis in the second phase.

## Chapter 4. Results

This study utilized a variety of methods to examine the use of social media by caregivers of children with Down syndrome for social support purposes. This section presents the data collected and analyzed for this study. The chapter is divided into the following sections: survey results, content analysis results, social media and social support, and summary of findings.

### Survey Results

The online survey was open for a period of 4 weeks. During that time, the survey was started 181 times, but 64 of those entries did not contain any responses. One person declined the electronic consent and 16 people completed less than half of the survey. Only entries where respondents completed 50% or more of the survey were used in the dataset. The number of entries in the dataset was 100. Within the dataset, the highest number of responses for any single question was 100 and the lowest number of responses for any single question was 83.

The online survey consisted of a total of 18 questions. The first question was an electronic consent to participate in the survey. Most of the questions were multiple choice or multiple response formats. Several questions were text boxes allowing respondents to provide answers that were not forced-answer choices. The survey also included three open-ended questions.

**Survey consent.** The first section of the survey explained the survey purpose, a statement of confidentiality, and information about the researcher. In order to continue on with the survey, respondents were asked to provide their electronic consent to participate. One respondent declined to participate. All 100 of the respondents in the dataset agreed to participate.

**Question 1.** Question 1 asked respondents to: *Please list up to five websites you visit to get Down syndrome-related information or support.* For this question, all responses were used

regardless of survey completion. Of the 346 websites listed by respondents, 127 websites were unique. The top three types of Down syndrome-related sites were: Facebook groups (137), BabyCenter groups (59), and individual blogs (53).

**Question 2.** Question 2 asked respondents to: *Please write down the name or URL (http://...) of the website you engage with the most for Down syndrome-related information or support.* Of the 100 respondents in the dataset, 97 indicated the name or URL of the preferred website. The responses were placed into social media categories with 56% falling into *social networking sites*, 34% into *discussion forums*, 6% into *individual blogs*, and 4% into other types of sites (mostly websites of various Down syndrome-related organizations).

The next six questions (Q3-Q8) related directly to the respondent's answer in question 2. In the online survey, the respondent's answer to question 2 was automatically piped into the related questions. Going forward, the respondent's answer from question 2 will be referred to as the *preferred site*.

**Question 3.** Question 3 asked: *How often do you visit [preferred site]?* Most of the respondents (96%) in the dataset indicated high frequency levels in their engagement with the preferred site (see Table 4). Almost three fourths (72%) of the respondents visited the site on a daily basis and another 22% visited the site at least two to three times a week. The remaining respondents indicated moderate to low frequency levels and, not surprisingly, no respondents selected the *never* answer option.

Table 4

*How Often Do You Visit [Preferred Site]?*

Answer Options	Response Count	Response %
Daily	71	72%

(continued)

Answer Options	Response Count	Response %
1-3 times a week	24	24%
1-3 times a month	2	2%
Less than once a month	2	2%
Never	0	0%
Total	99	100%
Missing data	1	

*Note. (n = 99)*

**Question 4.** Question 4 asked: *How long have you utilized [preferred site]?* The length of time respondents had used the site was fairly evenly distributed between *less than a year* and *3 years or longer* (see Table 5). The *1-2 years* response had the highest frequency (29%) and the *2-3 years* response had the lowest frequency (18%).

Table 5

*How Long Have You Utilized [Preferred Site]?*

Answer Options	Response Count	Response %
3 years or longer	25	25%
2-3 years	18	18%
1-2 years	29	29%
Less than a year	28	28%
Total	100	100%
Missing data	0	

*Note. (n = 100)*

**Question 5.** Question 5 asked: *How often do you engage in the following activities on [preferred site]?* Frequency levels varied widely for the different types of engagement activities (see Table 6). In the first activity, 94% of respondents indicated that they read or viewed content posted by others on a frequent basis (daily or at least once a week). Activity 2 (I comment on or

reply to content posted by others) and activity 3 (I post my own content) saw a more even distribution of frequency levels. Activity 4 (I help organize, moderate, or lead the group) received a high level of *never* responses (69%) but 16% *did* indicate engagement in this type activity on a daily basis. It seems that although many do not moderate or lead a group, for those who do participate in that way, it is a frequent activity.

Table 6

*How Often Do You Engage in the Following Activities on [Preferred Site]?*

	Daily	1-3 times a week	1-3 times a month	Less than once a month	Never	Total
1. I read or view content posted by others. ( <i>n</i> = 100)						
Response Count	73	21	3	2	1	100
Response %	73%	21%	3%	2%	1%	100%
2. I comment on or reply to content posted by others. ( <i>n</i> = 100)						
Response Count	30	39	14	10	7	100
Response %	30%	39%	14%	10%	7%	100%
3. I post my own content (text, photos, videos, audio, etc.). ( <i>n</i> = 100)						
Response Count	16	21	28	25	10	100
Response %	16%	21%	28%	25%	10%	100%
4. I help organize, moderate, or lead the group. ( <i>n</i> = 100)						
Response Count	16	4	4	7	69	100
Response %	16%	4%	4%	7%	69%	100%

**Question 6.** Question 6 asked respondents to indicate on a 4-point scale (1 = strongly disagree, 4 = strongly agree) their agreement with 17 statements that completed this sentence: *My reasons for utilizing [preferred site] include...* The 17 motivation statements aligned with the four social support categories examined in this study: informational support, emotional support,



belonging support, and active support. For the most part, informational support was a strong motivation for using the preferred site. The mean for statements relating to informational support was 3.39 with a standard deviation of 0.71 (see Table 7). Compared to the other statements in this group, respondents indicated more disagreement with statement 5 (19%), which regarded finding information to discuss with a healthcare provider. The *not applicable* option was selected seven times in this set of statements.

Table 7

*Informational Support Motivation Statements*

	1	2	3	4	N/A	Total	Mean	Std Dev
1. To better understand my child's condition	3	7	41	49	0	100	3.36	0.75
2. To receive advice about dealing with my child's condition	1	5	40	53	1	100	3.46	0.64
3. To find answers to specific questions	1	4	38	57	0	100	3.51	0.63
4. To find information that will help me make decisions	1	5	49	43	2	100	3.37	0.63
5. To find information that I can discuss with a healthcare provider	1	17	46	32	4	100	3.14	0.73
Total Count	7	38	214	234	7		3.39	0.71
Total %	1%	8%	43%	47%				

*Note.* 1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree, N/A = not applicable

Emotional support statements also received a high degree of agreement with a mean of 3.45 for the entire category and a standard deviation of 0.73 (see Table 8). While four of the statements in this category had means around the 3.5 range, statement 8 had a mean of 3.02 and the highest standard deviation of the group at 0.88. Compared to the others, this statement, which

regarded the expression of negative emotions, also had the highest rate of disagreement (28%) among the group. The *not applicable* option was selected 19 times in this set of statements.

Table 8

*Emotional Support Motivation Statements*

	1	2	3	4	N/A	Total	Mean	Std Dev
6. To be able to openly discuss how I feel	1	9	30	55	5	100	3.46	0.71
7. To find encouragement and/or reassurance	1	6	29	63	1	100	3.56	0.66
8. To express my negative emotions (fear, worry, anger, frustration)	4	23	33	33	7	100	3.02	0.88
9. To express my positive emotions (pride, joy, hope, excitement)	1	5	29	61	4	100	3.56	0.65
10. To find support and understanding	0	6	25	67	2	100	3.62	0.60
Total Count	7	49	146	279	19		3.45	0.73
Total %	1%	10%	30%	58%				

*Note.* 1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree, N/A = not applicable

Similar to the previous two categories, the belonging support statements also had strong agreement with a mean of 3.51 and a standard deviation of 0.70 (see Table 9). Ninety-three percent of respondents agreed with statement 11 (to connect with people who understand what I am experiencing) with 76% of them selecting *strongly agree*. The *not applicable* option was selected three times in this set of statements.

Table 9

*Belonging Support Motivation Statements*

	1	2	3	4	N/A	Total	Mean	Std Dev
11. To connect with people who understand what I am experiencing	1	6	17	76	0	100	3.68	0.63
12. To find a sense of belonging to a group	1	8	34	55	2	100	3.46	0.69
13. To not feel alone	3	7	37	52	1	100	3.39	0.75
Total Count	5	21	88	183	3		3.51	0.70
Total %	2%	7%	30%	62%				

*Note.* 1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree, N/A = not applicable

Unlike the first three categories, the active support statements had strong levels of disagreement and high opt out rates with respondents selecting *not applicable* 50 times among the four statements (see Table 10). As a whole, the active support statements had a mean of 3.00 with a standard deviation of 0.93. Statement 14 (to help and provide support to others) had the highest mean (3.62) with a standard deviation of 0.53. Statement 17 (to raise funds for Down syndrome-related issues) elicited the strongest disagreement with 45% disagreeing and 25% strongly disagreeing with the statement. It had the lowest mean (2.17), the highest standard deviation (0.94), and the highest number of respondents opting out by selecting *not applicable* (29).

Table 10

*Active Support Motivation Statements*

	1	2	3	4	N/A	Total	Mean	Std Dev
14. To help and provide support to others	0	2	33	62	2	99	3.62	0.53
15. To advocate for Down syndrome-related issues	1	26	31	33	9	100	3.05	0.84
16. To raise awareness about Down syndrome-related issues	4	25	35	26	10	100	2.92	0.86
17. To raise funds for Down syndrome-related issues	17	31	13	8	29	98	2.17	0.94
Total Count	22	84	112	129	50		3.00	0.93
Total %	6%	24%	32%	37%				

*Note.* 1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree, N/A = not applicable

Overall, respondents indicated high agreement levels for most of the statements. As a group, belonging support had the highest mean of 3.51 followed by emotional support (3.45), informational support (3.39), and lastly, active support (3.00). Looking at the statements individually (see Table 11), the motivation statements that garnered the most agreement were: *to connect with people who understand what I am experiencing* ( $M = 3.68$ ,  $SD = 0.63$ ), *to help and provide support to others* ( $M = 3.62$ ,  $SD = 0.53$ ), and *to find support and understanding* ( $M = 3.62$ ,  $SD = 0.60$ ). Interestingly, although active support statements as a group had the lowest mean, statement 14, which is part of active support, had the second highest mean.

Table 11

*Caregivers' Motivations for Using Preferred Site Sorted by Mean (high to low)*

Type of Social Support	Statements	Mean	Std Dev
Belonging	To connect with people who understand what I am experiencing	3.68	0.63
Active	To help and provide support to others	3.62	0.53
Emotional	To find support and understanding	3.62	0.60
Emotional	To express my positive emotions (pride, joy, hope, excitement)	3.56	0.65
Emotional	To find encouragement and/or reassurance	3.56	0.66
Informational	To find answers to specific questions	3.51	0.63
Informational	To receive advice about dealing with my child's condition	3.46	0.64
Belonging	To find a sense of belonging to a group	3.46	0.69
Emotional	To be able to openly discuss how I feel	3.46	0.71
Belonging	To not feel alone	3.39	0.75
Informational	To find information that will help me make decisions	3.37	0.63
Informational	To better understand my child's condition	3.36	0.75
Informational	To find information that I can discuss with a healthcare provider	3.14	0.73
Active	To advocate for Down syndrome-related issues	3.05	0.84
Emotional	To express my negative emotions (fear, worry, anger, frustration)	3.02	0.88
Active	To raise awareness about Down syndrome-related issues	2.92	0.86
Active	To raise funds for Down syndrome-related issues	2.17	0.94

*Note.* 1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree, N/A = not applicable

**Question 7.** Question 7 asked respondents to: *Indicate to what extent each statement describes your current interactions with others on [preferred site]*. This question was a modified Social Provisions Scale. Respondents indicated on a 4-point scale (1 = strongly disagree, 4 = strongly agree) the extent to which each statement described their social relationships on the site. *Not applicable* responses were given zero points. The eight statements aligned to the four social support categories and were summed up to produce a total score. The maximum possible score was 32 and the minimum possible score was zero. A higher score indicated a greater degree of perceived support from the relationships with people on the site. The mean score was 23.46 with a standard deviation of 5.80. With the scores placed into ranges, nearly a fifth (19%) of the respondents scored in the highest range (29-32 points), 28% in the 25-28 point range, and another 28% in the 21-24 point range. Sixteen percent of respondents scored between 17-20 points and 9% received a score of 16 and under (see Table 12).

Table 12

*Social Provisions Scale Total Scores*

Score Range	Response Count	Response %
29 to 32	19	19%
25 to 28	28	28%
21 to 24	28	28%
17 to 20	16	16%
16 and under	9	9%
Total	100	100%
Missing data	0	

*Note.* (n = 100)

The responses from the scale in question 7 were also analyzed by social support category. Each category contained two statements. The informational support statements had high

agreement with a mean of 3.31 and a standard deviation of 0.75 (see Table 13). Between those who agreed with the statements, there was an equal split between those who selected *agree* (45%) and *strongly agree* (45%). The high level of agreement with statement 2 (95%) indicates the presence of perceived trust in the people on the site. The *not applicable* option was selected seven times in this set of statements.

Respondents were fairly split in their agreement with the emotional support statements (see Table 13). The statements combined had a mean of 2.93 with a standard deviation of 0.86. Two thirds of the respondents agreed that they received emotional support from their relationships with others on the site while a third of the respondents did not. The *not applicable* option was selected 13 times in this set of statements.

The belonging support statements had the highest level of agreement among the four categories with a mean of 3.57 and a standard deviation of 0.55 (see Table 13). It is not surprising that most of the respondents agreed that there were others on the site who shared similar concerns and interests since they were specifically asked about sites they engaged in for Down syndrome-related purposes. The *not applicable* option was selected three times in this set of statements.

The active support category had the lowest mean at 2.43 with a standard deviation of 0.87 (see Table 13). In contrast to the emotional support statements, around two thirds of respondents *disagreed* with active support statements while only one-third agreed. The *not applicable* option was selected 11 times in this set of statements.

Respondents' perceived high levels of belonging and informational support from their interactions with others on their preferred site, but lower levels of emotional and active support. It is interesting that the active support statement, *to help and provide support to others* ( $M =$

3.62,  $SD = 0.53$ ) had one of the highest means in question 6, but the active support statement, *there are people who depend on me for help* ( $M = 2.42$ ,  $SD = 0.88$ ) had the lowest mean in question 7.

Table 13

*Indicate to What Extent Each Statement Describes Your Current Interactions With Others on [Preferred Site].*

	1	2	3	4	N/A	Total	Mean	Std Dev
<i>Informational Support Statements</i>								
1. There is someone I could talk to about important decisions regarding my child's care.	4	12	40	40	4	100	3.21	0.82
2. There are trustworthy people I could turn to for advice if I were having problems.	2	3	46	46	3	100	3.40	0.66
Subtotal	6	15	86	86	7		3.31	0.75
Subtotal %	3%	8%	45%	45%				
<i>Emotional Support Statements</i>								
3. I have relationships that provide me with a sense of emotional security and well-being.	3	25	40	26	6	100	2.95	0.82
4. I feel a strong emotional bond with at least one other person.	4	31	28	30	7	100	2.90	0.91
Subtotal	7	56	68	56	13		2.93	0.86
Subtotal %	4%	30%	36%	30%				
<i>Belonging Support Statements</i>								
5. There are people who have the same concerns and interests as I do.	0	1	35	63	1	100	3.63	0.51
6. I feel part of a group of people who share my concerns and interests.	0	5	37	56	2	100	3.52	0.60
Subtotal	0	6	72	119	3		3.57	0.55
Subtotal %	0%	3%	37%	60%				

(continued)



	1	2	3	4	N/A	Total	Mean	Std Dev
<i>Active Support Statements</i>								
7. There are people who depend on me for help.	11	47	23	14	5	100	2.42	0.88
8. I feel personally responsible for the well-being of other people on the site.	10	45	25	13	6	99	2.44	0.87
Subtotal	21	92	48	27	11		2.43	0.87
Subtotal %	11%	49%	26%	14%				

*Note.* 1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree, N/A = not applicable

**Question 8.** Question 8 asked: *Why do you use [preferred site] more than other online resources for Down syndrome-related information and support?* Eighty-nine respondents answered this open-ended question. Their responses were coded using an iterative process of identifying common keywords and topics to create a list of categories encompassing the scope of responses (see Table 14). Responses often fell into multiple categories. The most frequent responses fell into two categories: *belonging support* (33%) and *informational support* (33%). Those who indicated reasons relating to belonging support talked about how the site provided personal connections and camaraderie and reduced feelings of isolation. Respondents whose answers fell into the informational support category mentioned the quantity (abundance) of information found on the site as well as the accuracy, timeliness, and variety of the advice, answers, and topics. *Peer-to-peer support* was also frequently mentioned in the responses (30%). Caregivers liked the ability to connect with others who had children in the same age range and/or with the same condition as well as with those who had gone through similar experiences. Conversely, 20% of respondents indicated *diversity* as a one of their reasons for using the site. Reasons related to diversity included access to larger groups, to different perspectives, and to a variety of experiences. Reasons relating to emotional support (understanding, encouragement) and to the technology interface (convenience, accessibility, interactivity) were each mentioned in

22% of the responses. Several respondents (17%) appreciated the ability to learn from and about real world experiences as opposed to other sites and places where their child's condition was spoken about in clinical or medical terms. Twelve responses mentioned active support related items such as helping others and advocacy efforts and 10 responses mention reasons relating to site activity including frequent updates, effective moderation, and robust interaction.

Table 14

*Why Do You Use [Preferred Site] More Than Other Online Resources for Down Syndrome-Related Information and Support?*

Category	Keywords and Topics	Response Count	Response %
Belonging support	reduce isolation, personal connections, camaraderie	29	33%
Informational support	quantity, current, accurate, resources, variety of topics, advice and answers	29	33%
Peer-to-peer support	same age of children, similar condition, similar experiences	27	30%
Emotional support	encouragement, safe place, understanding	20	22%
Technology interface	familiarity or first site used/found, convenience, search ability, accessibility, interactive tools, well-maintained	20	22%
Diversity	larger group, diverse group, diverse perspectives	18	20%
Real world experiences	non-clinical, non-medical	15	17%
Active support	help others, advocacy, own/moderate	12	13%
Activity	active group, updated frequently, well-moderated, interactive	10	11%

*Note.* ( $n = 89$ )

**Question 9.** Questions 9 asked: *How do you determine whether or not the information you find online is trustworthy, especially in terms of accuracy, credibility, and relevance?*

Ninety-one caregivers responded to this open-ended question. Utilizing the same coding

technique as question 8, responses were categorized into seven methods for determining information reliability (see Table 15). A caregiver's response often contained more than one method. Performing further or additional research was the most frequent method respondents employed (38%). Validating sources by checking references and multiple sources followed closely (34%) along with consulting professionals such as healthcare providers and specialists (29%). Additional methods included following one's intuition, viewing information as opinions and suggestions, consulting other parents, and using authority sources such as Down syndrome-related organization sites.

Table 15

*How Do You Determine Whether or Not the Information You Find Online is Trustworthy, Especially in Terms of Accuracy, Credibility, and Relevance?*

Category	Keywords and Topics	Response Count	Response %
Perform further research	more research, own research	35	38%
Validate sources	check multiple sources, check references	31	34%
Consult professionals	doctors, specialists, therapists, educators, etc.	26	29%
Intuition	common sense, trust the source, personal experience	20	22%
View as opinions, individual experiences, and suggestions	use as starting off point, take with grain of salt	19	21%
Consult peers	other parents	9	10%
Use authority sources	organizations, government, medical	7	8%

*Note.* ( $n = 91$ )

**Question 10.** Question 10 asked respondents: *If you have attended face-to-face (FTF) Down syndrome support groups, please describe the differences you have experienced between face-to-face support communities and online support communities.* The eighty-three responses to

this open-ended question were coded using the same process described in questions 8 and 9 (see Table 16). Compared to the previous two open-ended questions, this question elicited more disagreement between responses. Some respondents felt that there was less fear of judgment or of causing offense in online support communities while others felt that there was less fear of judgment or of causing offense in the face-to-face environment. Some thought relationships online were deeper; others felt the face-to-face environment produced more meaningful relationships. Although many mentioned positive experiences with face-to-face support groups, the majority of responses leaned more favorably towards online support groups. Twenty-eight percent of respondents had never attended a face-to-face group or did not think there were any significant differences.

The most frequently mentioned difference between online and face-to-face support groups was the ability to be more open and honest online, which is in some part due to the anonymity the online environment affords. Thirty-one percent of the respondents felt that it was easier to open up, be honest, or ask potentially embarrassing questions online. Several caregivers mentioned the benefit of online support groups for those who are shy or private. Another frequently cited difference was the access online support groups provided to diverse opinions, perspectives, and experiences. Many noted that their local groups did not have children of the same age or with same specific conditions. Online, they were able to access from a worldwide net of caregivers, others with similar experiences, concerns, beliefs, etc. Additional benefits included the convenience of being able to access support at any time and without having to travel. Several caregivers noted that there were no local groups even available. For one caregiver who was deaf, the online community was the only way social support was accessible to her.

The strongest argument for face-to-face support groups was the personal connections and relationships caregivers were able to forge with people in real life. Twenty-nine percent of respondents indicated some type of personal connection or contact as a benefit of local support groups. Many noted the enjoyable and engaging aspect of being able to meet with people. A few respondents felt it was easier to trust others in the face-to-face setting and that there was less negativity than in online environments.

Table 16

*If You Have Attended Face-to-Face Down Syndrome Support Groups, Please Describe the Differences You Have Experienced Between Face-to-Face Support Communities and Online Support Communities.*

Category	Keywords and Topics	Response Count	Response %
Online - openness and anonymity	easier to be open and honest, easier to ask potentially embarrassing questions, less fear of judgment or causing offense, less pressure than FTF especially for shy or private people	26	31%
FTF - personal connections	stronger connections and relationships, real human contact, local connections and resources, engaging and enjoyable	24	29%
Online - better access	access to diversity (opinions, perspectives, experiences), access to similarities (ages, conditions, beliefs, experiences)	23	28%
Online - convenience	more accessible, more efficient, access to archives	17	20%
Online-information	source of information, resources, and knowledge	7	8%
FTF - trust	easier to trust others, less negativity, less fear of judgment or causing offense	5	6%
Not applicable	have not attended, no significant difference	23	28%

*Note.* ( $n = 83$ )

**Questions 11-17.** Questions 11 to 17 asked respondents various questions about their background and that of the child in their care. The data collected from these questions were used to describe the sample in the previous chapter (see Table 3). A Pearson product-moment correlation coefficient was computed to assess the relationship between various variables including several from questions 11 to 17. Although there were many significant correlations, only a handful provided meaningful information. Meaningful correlations will be discussed in the following sections.

**Summary of survey.** The online survey portion of the study provided insight into caregivers' engagement with social media for Down syndrome-related purposes. The caregivers in the dataset were very active online with over 70% visiting the preferred Down syndrome-related site on a daily basis to read or view content posted by others and around 70% commenting or replying to content posted by others on a frequent basis. Respondents visited their preferred sites for various reasons. The most popular reasons were: *to connect with people who understand what I am experiencing* (belonging support), *to help and provide support to others* (active support), and *to find support and understanding* (emotional support).

When looking at how interactions with others on the preferred site impacted perceptions of social support outcomes, respondents' perceived high levels of belonging and informational support, but lower levels of emotional and active support. This is corroborated by the open-ended responses to question 8, which asked respondents why they utilized the preferred site over other sites. Reasons relating to belonging and informational support were mentioned in 66% of the responses.

When considering differences between online and face-to-face support groups, the strength of the online environment was the ability to be more open and honest due to the

anonymity it afforded. The benefit of face-to-face groups however was the ability to build stronger connections and have real human contact.

### **Content Analysis Results**

In question 1 of the online survey, respondents were asked to list up to five websites they utilized for Down syndrome-related purposes. The top two types of sites listed were Facebook groups (137) and BabyCenter groups (59). One group from each of these platforms was selected for further analysis. In addition to the content on the site, the site's structure and design features were also analyzed. Table 17 describes the various aspects of the two sites. Although one is categorized as a social network, and the other as a discussion forum, both platforms are almost identical. The biggest difference can be found in the area of identity management. On Facebook, group member identities are linked to their individual Facebook profiles. Most Facebook users display their real full name, as it is a way for them to connect with their social network (friends and families). Depending on how their privacy levels are set, significant levels of personal information can be discovered about individuals. Group members are able to "friend" or connect with one another outside of the group setting. BabyCenter, however, is not a social networking site and contact between members is limited to activity within the group. Identity profiles of group members contain minimal amounts of real personal information. By default, unless members post additional information, the only visible information on their profile is their identity handle and the date they joined BabyCenter. This makes it much easier to remain anonymous compared to Facebook groups.

Table 17

*Comparison of Website Structure and Design Features of Analysis Sites*

Features	Facebook Groups	BabyCenter Groups
Social media classification	Social networking site	Discussion forum
Access	Only people logged into Facebook can join or view content on open groups. Group administrator approval is required to join and view content on closed groups.	Anyone can view content on public groups, but only those logged into the site can post or comment. Group owner approval is required to join private groups.
Moderation structure	Groups are moderated by group administrators.	Groups are moderated by group owners.
Participation structure	Users can post text or media and comment on content posted by others.	Users can post text or media and comment on content posted by others.
Content structure	Content is displayed with the most recent activity at the top. Activity includes post publishing and comments made to the post.	Content is displayed with the most recent activity at the top. Activity includes post publishing and comments made to the post.
Content feedback	There are two levels of feedback: users can comment on content or can “like” the content, which is a quick way to show positive validation without commenting	Users can comment on content or can give the content author a “hug” which is a quick way to show positive validation without commenting.
Identity management	Author identities have strong visibility as they are tied to their Facebook profile. Identity handles are usually the real full names of the author and depending on the privacy levels of their individual profiles, their identity is very public.	Author identities have weak visibility. Identity handles are usually not real names and personal profiles only contain minimal information such as length of membership, groups the user is a part of, and group activity. It is easy to remain anonymous.

**Facebook group.** Facebook is social networking platform that allows people to connect with others online. Facebook *groups* are dedicated spaces within the platform that allow specific sets of people to connect and share. For this study, a Facebook group for parents of children with Down syndrome was selected for analysis. At the time of review, the group had 13,221 members



and 14 administrators. Capturing data on Facebook groups can be difficult because posts are displayed based on recent activity, not chronologically by post published date. Anytime a comment is made on a post, that post rises to the top. In order to capture stable data, a snapshot was taken of all the posts from a prior date. Any post published on that specific date was used for analysis. The number of comments and “likes” on each post at the time the snapshot was taken was used in the analysis. The posts were coded using an iterative process of identifying common keywords and topics to create a list of categories encompassing the scope of posts. The same was done with the BabyCenter posts and a master list was used to analyze the content on both sites. Once posts were placed into categories, the number of *likes* and the number of *comments* each type of post received was collected and averaged (see Table 18).

In the Facebook group, more than half of the posts that were analyzed contained expressions of positive emotions such as pride, excitement, and happiness. Many of these posts contained photos and praise for their child. Although there was a wide range in the responses to these types of posts, they averaged 140 *likes* and 10 comments per post. There were far fewer posts expressing negative emotions (5%) but they averaged significantly more comments per post (70) than those expressing positive emotions. In this case, it was due to a few posts expressing outrage against another Facebook group that was posting highly discriminatory and offensive content about people with Down syndrome. The thread of comments became conversations between group members not only expressing outrage but also coming up with action plans for petitioning Facebook to take down the site and fight discrimination.

Content related to a child’s health was found in 16% of the posts. In this dataset, health-related *medical* posts discussed topics such as drugs, hospitalizations, and genetics. This category had a high number of average *likes* per post (251) and average comments per post (45)

due to the sympathizers and well-wishers on several posts about a child's hospitalization. Health-related *non-medical* posts discussed health topics that were not medical in nature such as development-related issues (speech, motor skills, etc.) and general health issues children face (eating, teething, sleeping, etc.). These types of posts often solicited the group for advice or recommendations for dealing with the issue.

Facebook group members showed a warm welcome to new members of the group who introduced themselves. These 13 posts (16%) averaged 230 *likes* and 25 comments per post. Another 13 posts contained links or information about resources. There were one or two posts in the remaining categories: education-related, parenting-related (Down syndrome-specific and general), and reviews and recommendations.

Table 18

*Thematic Categories Found in Facebook Group Content*

Category	Post Count	Post %	Avg. # of Likes per Post	Avg. # of Comments per Post
Education-related	1	1%	1	0
Emotional expression: negative	4	5%	25	70
Emotional expression: positive	45	54%	140	10
Health-related: child medical	5	6%	251	45
Health-related: child non-medical	8	10%	4	6
Health-related: parent	-	-	-	-
Introduction	13	16%	230	25
Link or resource information	13	16%	24	4
Parenting-related: DS-specific	2	2%	34	33
Parenting-related: general	2	2%	22	6
Reviews and recommendations	2	2%	25	15

*Note.* ( $n = 83$ )

**BabyCenter group.** BabyCenter is website about parenting and pregnancy. It provides a wide range of information for new and expecting parents. One component of the site is BabyCenter Communities, a platform that provides designated spaces for people to form groups around shared interests and experiences. For this study, the Down syndrome group on BabyCenter community was used for analysis. At the time of review, the group had 3,587 members and 9 group owners. Like the Facebook group, it was necessary to capture a snapshot of the posts to be used in the survey since new activity was continually occurring and changing the order of the posts. For this analysis, posts published during 20-day period were used and the number of comments and “hugs” on each post were taken from the snapshot. Compared to the Facebook group, this group has a much smaller membership and was less active; 20 days of data resulted in 100 posts. The same set of categories was used to code the posts in this dataset (see Table 19).

Around a third (34%) of the posts in the dataset contained expression of positive or negative emotions. Negative emotions expressed by post authors included anger, fear, frustration, worry, guilt, hurt, confusion, sadness, and anxiety. Many times these posts also contained health-related or Down syndrome-specific parenting-related issues. Posts expressing negative emotions received the second highest average number of hugs per post (7) and one of the highest average number of comments per post (13). Fourteen posts (14%) expressed positive emotions (joy, pride, happiness, excitement) and elicited the highest average number of hugs per post and an average of nine comments per post. The average number of hugs and comments for these types of posts would have been higher if an outlier was not removed from the calculations. The outlier post asked members to post photos of their children in the comments and received 25 hugs and 575 comments.

Over a third (36%) of the posts were health-related, which was more than twice the percentage of health-related posts on the Facebook group. These included posts regarding child-related medical and non-medical issues as well as parent-related health issues. Genetics and miscarriage were frequent topics on the parent health-related posts, which had the highest average number of comments per post (14).

Table 19

*Thematic Categories Found in BabyCenter Group Content*

Category	Post Count	Post %	Avg. # of Hugs per Post	Avg. # of Comments per Post
education-related	11	11%	0	9
emotional expression: negative	20	20%	7	13
emotional expression: positive	14	14%	10*	9*
health-related: child medical	17	17%	3	10
health-related: child non-medical	13	13%	1	11
health-related: parent	6	6%	6	14
introduction	-	-	-	-
link or resource information	14	14%	1	6
parenting-related: DS-specific	15	15%	5	13
parenting-related: general	11	11%	0	7
reviews and recommendations	12	12%	0	6

*Note.* ( $n = 100$ )

\* One post was removed when calculating the averages because it was an outlier with an unusual number of hugs (25) and comments (575). The post was a request for members to post pictures of their children in the comments section, which resulted in the high comment count.

**Summary of content analysis.** Although the Facebook group and the BabyCenter group shared many of the same characteristics in terms of site features and designs, the content on these two specific sites differed greatly. Table 20 displays the percentage of posts for each category. The majority of the Facebook posts were social or emotional in nature with many posting photos

of their children and providing status updates. Although there were several posts that were social/emotional in nature as well, the majority of the posts in the BabyCenter group were requests for advice, suggestions, and recommendations for various things from health related issues to parenting tips. The BabyCenter group seemed to lean more towards providing informational support and the Facebook group towards emotional support.

Table 20

*Comparison of Thematic Categories Between Facebook Group and BabyCenter Group*

Category	Facebook Post % ( <i>n</i> = 83)	BabyCenter Post % ( <i>n</i> = 100)
education-related	1%	11%
emotional expression: negative	5%	20%
emotional expression: positive	54%	14%
health-related: child medical	6%	17%
health-related: child non-medical	10%	13%
health-related: parent	-	6%
introduction	16%	-
link or resource information	16%	14%
parenting-related: DS-specific	2%	15%
parenting-related: general	2%	11%
reviews and recommendations	2%	12%

### **Social Media and Social Support**

For parents of children with genetic conditions like Down syndrome, the experience of first receiving the diagnosis is often shocking and can be described as a crisis situation (Selikowitz, 2008; Skotko, 2005). After the diagnosis, parents continue to experience high levels of emotional stress as they deal with the demands of caring for a child with special needs (Gunderson, 2011; Krahn, 1993; Mullins, 1987; Singer & Irvin, 1989). Seeking social support is

a key strategy for coping with stressful situations and online social media applications have become a popular method for obtaining that support.

The purpose of this study was to examine how caregivers of children with Down syndrome use social media to access social support. The uses and gratifications approach, which asserts that media use can be explained by the user's motives and needs (Katz, Blumler, & Gurevitch, 1973), was used as framework for this study. The use of social media for support purposes can result in a variety of benefits or gratifications that can be categorized under four of Weiss' (1974) social support provisions:

- Informational support (guidance and information)
- Emotional support (emotional closeness providing a sense of security)
- Belonging support (the sense of belonging to a group similar to oneself)
- Active support (the sense that one is needed by others)

Gratifications can be further differentiated between gratifications *sought* and gratifications *obtained* (Rayburn & Palmgreen, 1984). This implies that caregivers' motivations (gratifications sought) for using social media may be different than their perceived social support outcomes (gratifications obtained). Utilizing this framework to guide the research, the following research questions were derived for this study.

**Research questions.**

RQ1. How do caregivers use social media for social support purposes?

RQ2. What are caregivers' primary motivations for using social media for social support purposes?

RQ3. How does the use of social media mediate caregivers' perception of social support outcomes?

**Social media use.** The first research question (RQ1) sought to examine ways in which caregivers used social media for social support purposes. The first four questions of the online survey as well as correlations computed with other variables were used to answer this question. This section will present findings on the types of social media used by caregivers, the length of time and the frequency with which caregivers utilized social media, and the frequency with which caregivers participated in various activities on social media sites.

***Types of social media.*** Social networking sites and discussion forums were the most popular types of social media applications caregivers utilized for Down syndrome-related purposes. Specifically, various Facebook groups and BabyCenter groups were cited most frequently in the survey. Individual Down syndrome-related blogs were also mentioned but far less frequently than the first two social media categories.

***Length and frequency of use.*** The caregivers in this dataset were very active users of social media for Down syndrome-related purposes. Seventy-two percent visited their preferred site on a daily basis and another 24% visited the site at least once a week. Respondents were users of their preferred sites for various lengths of time. Three fourths of the respondents had used the site for less than 3 years and a fourth of the respondents had used the site for 3 years or longer. There was a significant correlation between the length of time respondents used the site and the length of time they had been caregivers to an individual with Down syndrome,  $r(100) = .55, p < .01$ .

***Frequency of engagement activities.*** Respondents used social media by engaging in various activities. The most frequent activity was reading or viewing content posted by others. Almost three fourths (73%) of the respondents engaged in this activity on a daily basis and another 21% did so at least once a week. Preece (2000) labeled users who only engaged in this

way as *lurkers*. Although it is the least visible type of activity, lurking is a significant form of engagement that can produce beneficial outcomes (Lave & Wenger, 1991; van Uden-Kraan et al., 2008). There was a strong positive correlation between frequency of site visits and reading or viewing content posted by others,  $r(99) = .85, p < .01$ . Higher frequencies in site visits were correlated with higher frequencies in reading or viewing activity.

As the participatory nature of the activity level increased, the frequency levels decreased. Compared to the 94% of respondents who read content posted by others on a frequent basis (at least once a week), only 69% of respondents commented on content posted by others with the same frequency, and only 37% posted their own content at least once a week. The activity of organizing, moderating, or leading a group had the lowest level of frequency with 69% of respondents selecting the *never* answer option and only 20% doing so on a frequent basis. It is interesting to note that although not many people engaged in moderating activities, for most of the people who did do so, it was a daily activity.

**Social support gratifications sought.** The second research question (RQ2) sought to examine caregivers' social support motivations for using social media. The primary source of data for this question was from question 6, which asked respondents to indicate their level of agreement with 17 statements regarding their reason for utilizing the preferred site on a 4-point scale (1 = *strongly disagree*, 4 = *strongly agree*). Additional supporting data was derived from the open-ended responses from question 8 as well as from the results of the content analysis on the two sites.

The 17 statements in question 6 aligned with the four social support categories examined in this study: informational support, emotional support, belonging support, and active support. The strongest motivation for social media use was the belonging support category ( $M = 3.51, SD$



= 0.70). The belonging support statement, *to connect with people who understand what I am experiencing*, received the highest mean ( $M = 3.68$ ,  $SD = 0.63$ ) among all the statements. In question 8 (*Why do you use the preferred site more than other online resources for Down syndrome-related information and support?*), reasons relating to belonging support were mentioned in a third of the responses. Camaraderie, reduction of feelings of isolations, and personal connections were some of the reasons respondents gave for utilizing the preferred site over other sites.

The second strongest motivation was emotional support, which, as a group, had a mean of 3.45 ( $SD = 0.73$ ). The emotional support statement, *to find support and understanding*, was tied for the second highest mean ( $M = 3.62$ ,  $SD = 0.60$ ) among all the statements. Twenty-two percent of the responses in question 8 mentioned emotional support activities such as encouragement, understanding, and feelings of safety as their reason for choosing the preferred site over others. In question 10, the most frequently mentioned benefit of online support groups was the ability to be open and honest, which corresponds to the emotional support statement, *to be able to openly discuss how I feel* in question 6. The Facebook group content analysis found that more than half (59%) of the posts contained emotional expressions (positive or negative) and that these posts elicited high levels of feedback from the group in the form of likes or comments. On the BabyCenter group, 35% of the posts contained emotional expressions and they too elicited relatively high levels of feedback in the form of hugs and comments compared to the other thematic categories identified in the analysis.

Informational support came in third with a category mean of 3.39 ( $SD = 0.71$ ). Within this group, the statement, *to find answers to specific questions*, had a fairly high mean of 3.51 ( $SD = 0.63$ ). In question 8, informational support-related keywords and topics were mentioned in

33% of the responses as reasons for utilizing the preferred site over others. In the BabyCenter group, 36% of the posts were health-related and 26% of the posts were parenting-related; many of these posts were requests for informational support in the form of advice, guidance, recommendations, and reviews.

Although active support came in as the weakest motivation ( $M = 3.0$ ,  $SD = 0.93$ ), the active support statement, *to help and provide support to others*, was tied for the second highest motivation among all the statements ( $M = 3.62$ ,  $SD = 0.53$ ); this incongruity explains the higher standard deviation for the category mean. In question 8, 13% of respondents mentioned *helping others* or other active support activities as reasons for using the preferred site. The desire to help and support others is reflected in the high number of feedback responses (comments, likes/hugs) on posts in the Facebook and BabyCenter groups.

**Social support gratifications obtained.** The third research question (RQ3) sought to examine how use of social media mediated caregivers' perceptions of social support outcomes. In question 7, respondents indicated their level of agreement with eight statements regarding their current interactions with others on their preferred site using a 4-point scale (1 = *strongly disagree*, 4 = *strongly agree*). This scale was used to assess the social support gratifications respondents actually received from their use of social media. In addition to responses from this question, the responses from the open-ended question (Q8-10) and the findings from the content analyses were used as data sources to answer this research question.

Just as belonging support was the top motivation for using social media, belonging support was also the top perceived outcome. Both of the belonging support statements in question 7 received strong levels of agreement: *there are people who have the same concerns and interests as I do* ( $M = 3.63$ ,  $SD = 0.51$ ) and *I feel part of a group of people who share my*

*concerns and interests* ( $M = 3.52$ ,  $SD = 0.60$ ). Ensnared within this construct of belonging support is the emphasis on peer-to-peer support. In question 8, respondents repeatedly mentioned having access to others who are like them to be an important aspect of their site choice.

Caregivers wanted to connect with others in similar situations and those who had children in the same age range or with similar conditions. In question 10, several respondents mentioned the ability to connect with others with similar situations, beliefs, and experiences as a significant benefit of the online environment, and one that is difficult to find in face-to-face support groups.

Statements regarding perceptions of informational support also had strong agreement ( $M = 3.31$ ,  $SD = 0.75$ ) on question 7. Respondents felt that there were people on their preferred site that they could talk to about their child's care and that they could turn to for advice. This finding was corroborated by the content analysis, especially on the BabyCenter group, where the exchange of information on health and parenting-related topics occurred in over half of the posts. Apomediary exchanges occurred frequently in the form of caregivers sharing reviews and recommendations on various topics including products, services, procedures, and tools. It is interesting to note, however, that although respondents felt that they could trust others on the site, in question 9, almost a third (29%) of the responses mentioned consulting professionals such as healthcare professionals to verify the accuracy and credibility of the information they find online. Thirty-eight percent said they performed further research and 21% said they viewed the information they find online as opinions and suggestions that need to be considered with a grain of salt.

Although reasons relating to emotional support were strong motivations for using social media, respondents had low levels of agreement with perceived emotional support outcomes ( $M = 2.93$   $SD = 0.86$ ). One reason for this disparity may be in the wording of the emotional support

statements in question 7, which focused on the emotional relationship or connection with others, not just the emotional support activities that were listed in question 6. Although many of the posts in the Facebook and BabyCenter groups contained expressions of positive and negative emotions, there was little evidence of sustained emotional relationships or connections. This is in line with the 29% of responses in question 10 that mentioned having stronger personal connections and relationships with people in face-to-face groups than in online support groups.

As with the active support motivation statements, the perceived active support outcome statements also received the lowest agreement ( $M = 2.43$ ,  $SD = 0.87$ ). However, although the statement, *there are people who depend on me for help*, had the lowest mean ( $M = 2.42$ ,  $SD = 0.88$ ) of all the statements in question 7, the motivation statement, *to help and provide support to others*, in question 6 had the second highest mean ( $M = 3.62$ ,  $SD = 0.53$ ) of the 17 statements. This seems to indicate that although caregivers desire to help and support others, their interactions are less relational and more passing in nature. This was seen in the Facebook and BabyCenter groups, where helping or supporting others often came in the form of responding to others' posts by commenting with words of encouragement or empathy, advice or guidance, reviews or recommendations, etc. Sustained relationships or connections were not visible in the analysis of the two groups. This is not to say that they did not occur, but in the platforms analyzed, deeper personal connections was not evident.

### **Summary of Findings**

When caregivers were asked to name the *one* site they used the most for Down syndrome-related information or support, an overwhelming majority (96%) named a social media application. More than half (56%) of the respondents named a social networking site like Facebook and a third (34%) named a discussion forum like BabyCenter. For this sample, social

media was indeed a popular medium for accessing social support. Responses from the online survey as well as results from a thematic content analysis of a Facebook group and a BabyCenter group were used to further examine caregivers' use of social media for social support. Specifically, the findings shed insight into how caregivers use social media for support purposes, their primary motivations for using social media, and the perceived social support outcomes of their social media use.

The caregivers in this study were active users of social media with a majority of them visiting their preferred sites on a daily basis. While the most frequent activity on these sites was reading content posted by others, many also posted content or comments at least once a week. Although only a handful of respondents were group moderators, organizers, or owners, many of them engaged in moderating activities a daily basis.

Caregivers' primary motivation for using social media was to connect with people who understood what they were experiencing. Having access to other parents with children the same age and/or with the same medical conditions was a significant motivation for using social media over face-to-face support groups. Behind belonging support, emotional support functions were the second strongest motivators for using social media. Caregivers wanted to find support and understanding and feel encouraged and reassured. Openly discussing feelings (including both positive and negative emotions) was a strong component of social media use as evidenced in the content analysis of the two social media sites. In their responses to the open-ended survey questions, caregivers repeatedly mentioned the importance of having a safe place to express oneself and to ask uncomfortable or potentially embarrassing questions without the fear of judgment. Additional motivations for social media use included informational and active support functions. Although active support as a category was the weakest motivation, the active support

statement, *to help and provide support to others*, had one of the strongest agreements. This desire to help and support others is reflected in the high number of feedback responses (comments, likes/hugs) on posts in the Facebook and BabyCenter groups.

Caregivers perceived various social support outcomes from their use of social media. In line with their motivations, belonging support was the highest perceived outcome of social media use. Caregivers felt that there were people who shared their same concerns and interests on their preferred social media site. The second highest perceived outcome of social media use was informational support. One function of this type of support was the sharing or requesting of information on health and parenting-related topics. Over half of the posts analyzed in the BabyCenter group contained this type of exchange. Another aspect of informational support was the ways in which caregivers acted as guides or apomediaries by sharing relevant information in the form of recommendations and reviews. Respondents indicated low levels of agreement with perceived emotional support outcomes although it was the second highest motivation. This may be due to the relational nature of the emotional support statements in questions 7 compared to the more activity-focused emotional support statements in questions 6. Although many of the posts in the Facebook and BabyCenter groups contained expressions of positive and negative emotions, there was little evidence of sustained emotional relationships or connections. Similarly, perceived active support outcomes also had low agreement levels even though providing help and support to others was a strong motivation for social media use. This too, seems to indicate that although caregivers desire to help and support others, their interactions are less relational and more passing in nature.

## **Chapter 5. Social Media and Social Support**

The purpose of this study was to examine how caregivers of children with health conditions use social media to access social support. Down syndrome is a health condition that affects one in every 691 babies born in the United States. Also known as Trisomy 21, this condition is the most commonly occurring genetic disorder and it is estimated that there are more than 400,000 people living in the United States with the condition (NDSS, n.d.). Although the range varies, people with Down syndrome experience physical and cognitive developmental delays and have an increased risk for certain medical conditions such as congenital heart defects, respiratory and hearing problems, Alzheimer's disease, childhood leukemia, gastrointestinal issues, and thyroid conditions (Centers for Disease Control and Prevention [CDC], 2013; GeneFacts, n.d.; Sherman et al., 2007.).

Parents of children diagnosed with Down syndrome and other genetic conditions experience high levels of emotional stress beginning from the moment they receive the initial diagnosis (Selikowitz, 2008; Skotko, 2005). For those who receive the diagnosis shortly after giving birth, the experience is even more difficult since they are already in an emotional and vulnerable state from the labor and delivery process. They have not had a chance to get to know their child as an individual before he or she is labeled with a syndrome or condition (Selikowitz, 2008; Skotko, 2005). Feelings of fear and anxiety are oftentimes exacerbated when healthcare professionals provide parents with a bleak outlook and point out only the negative aspects of the condition (Choi et al., 2011; Skotko, 2005; Skotko et al., 2009). Not knowing how the condition will impact their child's future prospects or what the probable medical, intellectual, or social consequences of the condition may be are also significant stressors for parents (Gunderson, 2011; McCallister et al., 2007). After the diagnosis, parents continue to experience stress as they

experience high levels of caretaking demands (Gunderson, 2011; Mullins, 1987; Singer & Irvin, 1989). They need to continually monitor their child's health status as well as manage multiple medical, therapy, and educational appointments (Krahn, 1993; Mullins, 1987; Singer & Irvin, 1989).

One strategy for coping with the stress of caring for a child with special needs is seeking social support, which can buffer and protect an individual from the negative effects of stress, crisis, or change (Cobb, 1976; Cohen & Syme, 1985; Kaplan, Cassel, & Gore, 1997; Stewart, 1993). Supportive actions can moderate stress in times of crisis and change and facilitate coping and adaptation. More and more, people are going online to access social support (Fox, 2011). Although local face-to-face support groups are a source of social support for some, for many who are working around a child's schedule and needs, going to a physical location at pre-designated times can be difficult, if not impossible (Coulson & Knibb, 2007; Weinberg, Schmale, Uken, & Wessel, 1995; Wright 2000; Sharf, 1997). The time and location independence of Internet communications, as well as the ease and speed of accessing online support from home, especially in light of work and family commitments, makes online support services a popular option over face-to-face support groups (Coulson & Knibb, 2007; J. Leimeister, Schweizer, S. Leimeister, & Krcmar, 2008). Social media applications provide a rich platform for communities to grow and develop online. They allow people to quickly and easily connect, form groups, and collaborate, as well as harness collective intelligence or the "wisdom of the crowds" (Shirky, 2008; Surowiecki, 2005).

### **Summary of the Study**

To examine how caregivers of children with Down syndrome use social media to access social support, this mixed methods explanatory sequential study utilized a uses and gratifications



framework, which asserts that media use can be explained by the user's motives and needs (Katz, Blumler, & Gurevitch, 1973). The use of social media for support purposes can result in a variety of benefits or gratifications that can be categorized under four of Weiss' (1974) social support provisions:

- Informational support (guidance and information)
- Emotional support (emotional closeness providing a sense of security)
- Belonging support (the sense of belonging to a group similar to oneself)
- Active support (the sense that one is needed by others)

Gratifications can be further differentiated between gratifications *sought* and gratifications *obtained* (Rayburn & Palmgreen, 1984). This implies that caregivers' motivations (gratifications sought) for using social media may be different than their perceived social support outcomes (gratifications obtained). Utilizing this framework to guide the research, the following questions were derived for this study.

### **Research questions.**

RQ1. How do caregivers use social media for social support purposes?

RQ2. What are caregivers' primary motivations for using social media for social support purposes?

RQ3. How does the use of social media mediate caregivers' perception of social support outcomes?

The study was conducted in two sequential phases. In the first phase, an online survey was used to collect quantitative data as well as qualitative data from open-ended questions. All of the survey respondents ( $N = 100$ ) were parents of children with Down syndrome. While the individuals in their care ranged from newborns to 18 years old, the majority were under 3 years

of age. In the second phase, two social media websites were selected based on survey responses to examine using a thematic content analysis.

## **Review of Findings**

When caregivers were asked in the online survey to name the *one* site they used the most for Down syndrome-related information or support, an overwhelming majority (96%) named a social media application. More than half (56%) of the respondents named a social networking site like Facebook and a third (34%) named a discussion forum like BabyCenter. Both of these applications fall into the same category within the social media classification matrix (see Table 1): high level of *self-presentation/self-disclosure* and medium level of *social presence/media richness*. Responses from the online survey as well as results from a thematic content analysis of a Facebook group and a BabyCenter group were used to further examine caregivers' use of social media for social support. Specifically, the findings shed insight into how caregivers use social media for support purposes, their primary motivations for using social media, and the perceived social support outcomes of their social media use.

**Caregivers and technology.** A national survey by the Pew Research Center found that caregivers of individuals with medical, behavioral, or other condition or disability were heavy technology users (Fox, Duggan, & Purcell, 2013). This was indeed the case for the caregivers in this study. The majority of respondents accessed their preferred sites on a daily basis. While the most frequent activity on these sites was reading content posted by others, many also posted content or comments at least once a week. Although only a handful of respondents were group moderators, organizers, or owners, many of them engaged in moderating activities a daily basis.

**Belonging support.** Caregivers' primary motivation for using social media was to connect with people who understood what they were experiencing. Having access to other

parents with children the same age and/or with the same medical conditions was a significant motivation for using social media over face-to-face support groups. Belonging support (the sense of belonging to a group similar to oneself) was also the highest perceived outcome of social media use. Caregivers felt that there were people who shared their same concerns and interests on their preferred social media site.

**Emotional support.** Following belonging support, emotional support functions were the second strongest motivators for using social media. Caregivers wanted to find support and understanding and feel encouraged and reassured. Openly discussing feelings (including both positive and negative emotions) was a strong component of social media use as evidenced in the content analysis of the two social media sites. In their responses to the open-ended survey questions, caregivers repeatedly mentioned the benefits the online environment afforded such as the ability to share openly and honestly, the ability to ask uncomfortable or potentially embarrassing questions, and the access it provided for those who are not comfortable in face-to-face settings. Anonymity in online support communities enables people to safely disclose information about themselves without fear of stigmatization and has been found to increase openness (Kiesler, Siegel, & McGuire, 1984; Wright, 2000; Wright & Bell, 2003). It also provides opportunities for those who are not comfortable in group settings or who do not enjoy being part of a formal group to access support without going to face-to-face meetings (Weinberg et al., 1995).

Although emotional support was the second highest motivation for social media use, that did not translate to perceived emotional support outcomes, which received one of the lowest levels of agreement. One explanation for this may be that while caregivers feel safe in these groups and can express themselves openly, the emotional support they receive is more in passing

and not relational. This was seen on the Facebook and BabyCenter groups where caregivers' interactions, for the most part, were through commenting or *liking/hugging* posts. There was little evidence of sustained emotional relationships or connections. Since the emotional support outcome statements are geared toward the relational aspect of emotional closeness and less on the actual emotional support activities, this would explain the disparity between emotional support motivation and outcome. In addition, one of the most frequently mentioned differences between online and face-to-face groups was the stronger personal connections and relationships with people in face-to-face groups.

**Informational support.** For the most part, informational support motivational statements such as *to find answers to specific questions* and *to receive advice about dealing with my child's condition* had strong agreement levels. Informational support also was the second highest perceived outcome of social media use. One function of this type of support was the sharing or requesting of information on health and parenting-related topics. Over half of the posts analyzed in the BabyCenter group contained this type of exchange. Another aspect of informational support was the ways in which caregivers acted as guides or apomediaries by sharing relevant information in the form of recommendations and reviews.

The national survey on peer-to-peer healthcare activity among adults in the United States (Fox, 2011) found that people turned to different sources depending on the nature of the issue related to the medical condition or concern. Healthcare professionals like doctors and nurses mattered most for technical issues related to a health condition such as an accurate medical diagnosis, information about prescription drugs or alternative treatments, and recommendations for a doctor, specialist, or medical facility. Fellow patients, friends, and family mattered most for emotional support in dealing with a health issue and for quick remedies for everyday health

issues. Both of these groups were found to be equally helpful in providing practical advice for coping with day-to-day health situations (Fox, 2011). This finding was reflected in the health and parenting-related posts on the social media sites analyzed in this study. When caregivers' were asked how they determined the accuracy, credibility, and relevance of the information they found online, almost a third (29%) indicated consulting professionals (doctors, specialists, therapists, educators, etc.) to verify what they read. The majority also performed further research and validated references and sources. Many respondents viewed the information found online as opinions, individual experiences, and suggestions that they could use as starting off points.

**Active support.** As a whole, active support statements had the lowest levels of agreement as both motivations and outcomes. However, one active support statement, *to help and provide support to others*, had one of the highest means within the 17 motivation statements. This desire to help and support others is reflected in the high number of feedback responses (comments, likes/hugs) on posts in the Facebook and BabyCenter groups. It is surprising then, that the perceived emotional support outcome statement, *there are people who depend on me for help*, received the lowest mean of the entire outcome statements. Like the disparity between emotional support motivations and outcomes, this too, seems to indicate that although caregivers desire to help and support others, their interactions are less relational and more passing in nature.

## **Implications**

This study gathered information on the way caregivers used social media to access social support. The findings shed insight into how caregivers use social media for support purposes, their primary motivations for using social media, and the perceived social support outcomes of their social media use. This information can provide a set of guidelines for other health or care-related online communities focused on providing social support. Examples of other such

communities include: caregivers of children with genetic or other health conditions or special needs, adoptive parents, caregivers of elderly parents, and caregivers of individuals with chronic diseases. Based on findings from this study, some key guidelines that can help such communities foster social support will be discussed in this section.

**Provide a way to find others.** This study found that caregivers' primary motivation for using social media was to connect with people who understood what they were experiencing. Although support communities may have a central focus (e.g. Down syndrome), within the community there can exist a range of different conditions, stages, and experiences. The Internet provides access to so many more people, making it possible to find others with the specific similarities. Providing ways for people to find and connect with others based on these specific similarities can help them receive more relevant support and information. This can be as simple as the ability to search keywords or can be more complex with the setup of various groups for children born the same year or with specific health conditions.

**Provide group moderation.** Caregivers in this study were strongly motivated by emotional support functions such as openly discussing how they were feeling and expressing both positive and negative emotions. This type of exchange is possible in the context of a safe environment where people are not afraid of being judged or attacked. Effective group moderation can ensure that the basic rules of the community are being enforced and take action on activities that make the group an unsafe place for open sharing and communication.

**Provide a search function.** Informational support is an important component of social support. Caregivers in this study used social media to find information and advice on a variety of health and parenting-related topics. The ability to quickly and easily find information on specific topics is especially useful for those who are lurkers on the site and do not want to post their own

content. Social media sites are often dynamic with new content continually being posted. Finding specific information that may have already been answered can be difficult without a robust search function. For those who do not want to post a question, wading through a large mass of information to find a specific answer can be frustrating and discouraging.

**Provide a way to connect deeper.** Caregivers in the study indicated low levels of agreement with statements regarding support outcomes that were relational in nature. Many did not feel that online support groups provided deep or real personal connections. Because most interaction on social media sites are in the form of comment threads that are visible by everyone in the group, it is difficult to have deeper or more meaningful conversations. While this may not be something that everyone in the group may desire, for those who do, providing a way to connect through something besides just commenting on a post can be a valuable support feature. This may be a direct or private messaging function or the ability to chat or instant message with others on the site.

**Provide a home base.** Online communities may benefit from a home base type of site that would be a central hub for connecting with others, finding information, and finding support. This site could use the guidelines discussed above to meet the social support needs of the community as well as provide additional services that make it a comprehensive resource. Privacy is an important aspect especially for communities dealing with minors and vulnerable populations. The home base should be a secure space that gives members privacy while allowing them to safely share and connect with others. The site can utilize existing social media spaces like closed Facebook groups or develop tools to live within the site. Providing a home base for communities focused around specific things like health conditions can prove to be a valuable tool that makes information and support easily searchable and accessible.

Based on the findings of this study, these guidelines can be used to promote social support outcomes in online communities. Although the caregivers were the focus of this study, these guidelines can be useful for a wide range of online communities where support is important focus. They can also be useful for organizations or groups seeking to provide an avenue for social support for their constituents.

### **Limitations and Recommendations for Further Study**

The survey used in this study consisted mainly of multiple-choice questions with predetermined answer options that were based on the literature and the researcher's experience with the Down syndrome online community. Because the answer options were pre-defined, there may be additional motivations or social support outcomes that were not captured in the data. The open-ended responses as well as the content analysis of the two sites helped alleviate this limitation to a certain extent.

The nature of social media is dynamic with new content constantly being produced. As such, capturing stable data on social media sites can be difficult. For the thematic content analysis on the two sites, it was necessary to take a snapshot of the site at a specific point in time and use that capture for the analysis. It was also helpful to use posts from a prior date as they are less likely to be updated.

While generalizations can be made about the use of social media for social support by any health or support-related online community, this study looked specifically at the caregiver community and more specifically at caregivers of a particular condition. For future studies looking at social media use, motivations, and outcomes, it will be useful to examine other online communities and make comparisons between caregivers' experiences and the experience of the individual with the health condition. An analysis of other types of social media applications



besides Facebook and BabyCenter would provide insight into different features of social media that may play a role in social support.

### **Concluding Remarks**

The use of social media in the healthcare arena is a rapidly growing and expanding phenomenon. Health 2.0 is changing the traditional boundaries between healthcare professionals, researchers, and patients. People can turn to different sources for different needs and for social support needs, the caregivers in this study turned to social media sites to access support from their peers. Connecting with others who understand and share the same concerns and experiences was the strongest motivation and the strongest perceived outcome of social media use. Within this community of peers, caregivers were able to find emotional support as well as relevant information. Social media also provided a way for caregivers to help and support each other.

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## APPENDIX A

### GPS IRB Exemption Notice

# PEPPERDINE UNIVERSITY

## Graduate & Professional Schools Institutional Review Board

November 10, 2014

Lydia Sunnie Kim  
[REDACTED]

Protocol #: E0914D07

Project Title: Caregivers and Online Social Support: A Uses and Gratification Examination of Health 2.0

Dear Ms. Kim:

Thank you for submitting your application, *Caregivers and Online Social Support: A Uses and Gratification Examination of Health 2.0*, for exempt review to Pepperdine University's Graduate and Professional Schools Institutional Review Board (GPS IRB). The IRB appreciates the work you and your faculty advisor, Dr. Polin, have done on the proposal. The IRB has reviewed your submitted IRB application and all ancillary materials. Upon review, the IRB has determined that the above entitled project meets the requirements for exemption under the federal regulations (45 CFR 46 - <http://www.nihtraining.com/ohsrsite/guidelines/45cfr46.html>) that govern the protections of human subjects. Specifically, section 45 CFR 46.101(b) (2) states:

(b) Unless otherwise required by Department or Agency heads, research activities in which the only involvement of human subjects will be in one or more of the following categories are exempt from this policy:

**Category (2) of 45 CFR 46.101**, research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless: a) Information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and b) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

In addition, your application to waive documentation of informed consent has been **approved**.

Your research must be conducted according to the proposal that was submitted to the IRB. If changes to the approved protocol occur, a revised protocol must be reviewed and approved by the IRB before implementation. For any proposed changes in your research protocol, please submit a **Request for Modification Form** to the GPS IRB. Because your study falls under exemption, there is no requirement for continuing IRB review of your project. Please be aware that changes to your protocol may prevent the research from qualifying for exemption from 45 CFR 46.101 and require submission of a new IRB application or other materials to the GPS IRB.

A goal of the IRB is to prevent negative occurrences during any research study. However, despite our best intent, unforeseen circumstances or events may arise during the research. If an unexpected situation or adverse event happens during your investigation, please notify the GPS IRB as soon as possible. We will ask for a complete explanation of the event and your response. Other actions also may be required depending on the nature of the event. Details regarding the timeframe in which adverse events must be reported to the GPS IRB and the appropriate form to be used to report this information can be found in the *Pepperdine University Protection of Human Participants in Research: Policies and Procedures Manual* (see link to "policy material" at <http://www.pepperdine.edu/irb/graduate/>).

Please refer to the protocol number denoted above in all further communication or correspondence related to this approval. Should you have additional questions, please contact Kevin Collins, Manager of the Institutional Review Board (IRB) at [gpsirb@pepperdine.edu](mailto:gpsirb@pepperdine.edu). On behalf of the GPS IRB, I wish you success in this scholarly pursuit.

Sincerely,

A handwritten signature in cursive script, reading "Thema Bryant-Davis".

Thema Bryant-Davis, Ph.D.  
Chair, Graduate and Professional Schools IRB

cc: Dr. Lee Kats, Vice Provost for Research and Strategic Initiatives  
Mr. Brett Leach, Compliance Attorney  
Dr. Linda Polin, Faculty Advisor

## APPENDIX B

### Permission Request to Distribute Survey Link

Dear \_\_\_\_\_,

Hello! My name is Lydia Sunnie Kim and I am a doctoral student in the Graduate School of Educational Psychology at Pepperdine University. I am also a parent of a three year old boy with a genetic condition (unbalanced translocation of chromosomes 12 and 18). The online Down syndrome community helped me as I coped with my child's diagnosis and special needs and continues to be a source of information and encouragement.

I am performing a research study on the use of social media for social support by caregivers of children with Down syndrome. This study will be beneficial in that it will help researchers understand how caregivers utilize online resources and its impact on perceptions of support. This can be valuable insight for the healthcare community, especially those who are the first points of contact for parents receiving their child's diagnosis.

I would like to obtain your permission to have a link to a short survey sent out to your members. The survey is completely confidential and voluntary. No identifying information will be collected.

With your permission, the survey would be sent out sometime in October 2014 and open to responses for a two-week period.

You can view a draft of the survey using the link below. I would welcome and appreciate any feedback you may have on the survey. Please let me know if you have any questions or concerns. I look forward to your response.

Draft Survey Link: <http://goo.gl/6AUMtW>

Thank you so much!

Lydia Sunnie Kim

## APPENDIX C

### Survey: Caregivers and Online Social Support

#### **SURVEY CONSENT**

##### **Introduction**

Hello! My name is Lydia Sunnie Kim and I am a doctoral student in the Graduate School of Educational Psychology at Pepperdine University. This survey is part of a research study I am doing for my dissertation on social media and social support. As a parent of an amazing three year old boy with a genetic condition (unbalanced translocation of chromosomes 12 and 18), the online Down syndrome community helped me as I coped with my child's diagnosis and special needs and continues to be a source of information and encouragement. This research is a tribute to this incredible community with hopes that it will shed insight into the ways social media impacts caregivers like us.

##### **Information**

This study will examine the use of online social support by caregivers of children with Down syndrome. The survey will inquire about the websites you use to gain Down syndrome-related support and information, your level of engagement on those sites, and the level of social support you receive from your participation in them.

The survey

- consists of 17 questions
- will take around 10 minutes
- will be open for two weeks.

Participation in this survey is completely voluntary. You do not have to answer every question and can stop at any time.

##### **Confidentiality**

Your responses will be confidential and no identifying information (e.g. name, email, IP address) will be collected. All data will be stored in a password-protected electronic format. The results of this study will only be used for scholarly purposes. Participation in the study is entirely voluntary.

##### **Risks/Benefits**

The only foreseeable risk associated with this study is the imposition on your time. For some, there may be the possibility of emotional discomfort when thinking about your child's diagnosis. If this is the case, please note that you can stop at any time. This study will be beneficial in that it will help researchers understand how caregivers utilize online resources for social support. This

can be valuable insight for the healthcare community, especially those who are the first points of contact for parents receiving their child's diagnosis.

## Contact

If you have any questions at any time about the study or the procedures that are being used, please contact me, Lydia Sunnie Kim, at [lydia.s.kim@pepperdine.edu](mailto:lydia.s.kim@pepperdine.edu). My dissertation advisor, Dr. Linda Polin, can be reached at [linda.polin@pepperdine.edu](mailto:linda.polin@pepperdine.edu).

**ELECTRONIC CONSENT:** Please select your choice below.

Clicking on the “agree” button below indicates that:

- you have read the above information
- you voluntarily agree to participate
- you are at least 18 years of age.

If you do not wish to participate in the research study, please decline participation by clicking on the “disagree” button.

- I agree (1)
- I disagree (end of survey) (2)

If I disagree (end of survey) Is Selected, Then Skip To End of Survey

## SECTION 2

Studies have shown that caregivers engage in a variety of online activities to gather health information and find social support. The following questions will help us understand how you use social media for Down syndrome-related purposes.

1. Please list up to five websites you visit to get Down syndrome-related information or support. This can include specific Facebook groups, discussion forums, blogs, your own blog, etc. Please provide URLs (<http://...>) if possible.

- (1) \_\_\_\_\_
- (2) \_\_\_\_\_
- (3) \_\_\_\_\_
- (4) \_\_\_\_\_
- (5) \_\_\_\_\_

Think of the ONE website that you engage with the most to get Down syndrome-related information or support. This can include specific Facebook groups, discussion forums, blogs, your own blog, etc.

2. Please write down the URL (<http://...>) of the website you engage with the most for Down syndrome-related purposes. \_\_\_\_\_

The next six questions will deal specifically with your response from question 2. The website you listed has been auto-populated in the next set of questions.

3. How often do you visit \${q://QID28/ChoiceTextEntryValue}?

- ☐ Daily (1)
- ☐ 2-3 Times a Week (2)
- ☐ Once a Week (3)
- ☐ 2-3 Times a Month (4)
- ☐ Once a Month (5)
- ☐ Less than Once a Month (6)
- ☐ Never (7)

4. How long have you utilized \${q://QID28/ChoiceTextEntryValue}?

- ☐ Less than 3 months (1)
- ☐ 3-6 months (2)
- ☐ 6-9 months (3)
- ☐ 9-12 months (4)
- ☐ 1-2 years (5)
- ☐ 2-3 years (6)
- ☐ 3 years or longer (7)

5. How often do you engage in the following activities on \${q://QID28/ChoiceTextEntryValue}?

	Daily (1)	2-3 Times a Week (2)	Once a Week (3)	2-3 Times a Month (4)	Once a Month (5)	Less than Once a Month (6)	Never (7)
I read or view content posted by others. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I post my own content (text, photos, videos, audio, etc.) and comment or reply to content posted by others. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I help organize, moderate, or lead the group. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6. My reasons for utilizing \$ {q://QID28/ChoiceTextEntryValue} include:

	Strongly Agree (1)	Agree (2)	Disagree (3)	Strongly Disagree (4)	Not Applicable (5)
To better understand my child's condition (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To receive advice about dealing with my child's condition (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To find answers to specific questions (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To find information that will help me make decisions (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To find information that I can discuss with a healthcare provider (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To be able to openly discuss how I feel (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To find encouragement and/or reassurance (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To express my negative emotions (fear, worry, anger, frustration) (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To express my positive emotions (pride, joy, hope, excitement) (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To find support and understanding (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To connect with people who understand what I am experiencing (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To find a sense of belonging to a group (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To not feel alone (13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To help and provide support to others (14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To advocate for Down syndrome-related issues (15)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To raise awareness about Down syndrome-related issues (16)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To raise funds for Down syndrome-related issues (17)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



7. For the next set of questions, indicate to what extent each statement describes your current interactions with others on  $\{q://QID28/ChoiceTextEntryValue\}$  (not in general).

	Strongly Agree (1)	Agree (2)	Disagree (3)	Strongly Disagree (4)	Not Applicable (5)
There are people who depend on me for help. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There are people who have the same concerns and interests as I do. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel personally responsible for the well-being of other people on the site. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel part of a group of people who share my concerns and interests. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have relationships that provide me with a sense of emotional security and well-being. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is someone I could talk to about important decisions regarding my child's care. (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There are trustworthy people I could turn to for advice if I were having problems. (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel a strong emotional bond with at least one other person. (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

8. Why do you use  $\{q://QID28/ChoiceTextEntryValue\}$  more than other online resources for Down syndrome-related information and support?

9. How do you determine whether or not the information you find online is trustworthy, especially in terms of accuracy, credibility, and relevance?

10. If you have attended face-to-face Down syndrome support groups, please describe the differences you have experienced between face-to-face support communities and online support communities.

### SECTION 3

This section will help us learn more about you and your relationship to an individual with Down syndrome.

11. What is your relationship to the individual with Down syndrome?

- ☐ Parent (1)
- ☐ Grandparent (2)
- ☐ Aunt or Uncle (3)
- ☐ Sibling (4)
- ☐ Guardian (5)
- ☐ Other: (6) \_\_\_\_\_

12. What is the age of the individual with Down syndrome under your care:

13. How long have you been a caregiver for an individual with Down syndrome?

14. How old are you?

- ☐ 18-29 years (1)
- ☐ 30-39 years (2)
- ☐ 40-49 years (3)
- ☐ 50 years or older (4)

15. What type of access do you have to health services?

- ☐ Private insurance (usually employment-based) (1)
- ☐ Public insurance (e.g. Medicaid) (2)
- ☐ No insurance (3)

16. What type of access does the individual with Down syndrome in your care have to health services?

- ☐ Private insurance (usually employment-based) (1)
- ☐ Public insurance (e.g. Medicaid) (2)
- ☐ No insurance (3)

17. Where do you live?

- ☐ City (1)
- ☐ Suburb (2)
- ☐ Rural (3)